CASE **13**

Implementing Policy Changes to Decrease Racial and Ethnic Disparities in Pediatric Asthma Outcomes

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Alex, a 12-year-old from Englewood, Chicago, Illinois, has asthma. His mother, Michelle, has spent the last decade looking for answers to keep her son's asthma attacks at bay. Alex's hacking cough has triggered multiple asthma attacks that have sent Michelle rushing to the emergency room with Alex six times over a recent 12-month period. These hospital runs meant many missed classes and school days; Alex has been falling behind. Michelle has shuttled him back and forth to multiple doctors, followed their orders, and agreed to have her son try multiple treatment regimens. Yet, asthma flareups have remained frequent. Michelle has often felt alone, overwhelmed, and filled with unanswered questions.

One day in Fall 2010, the cell phone rang while Michelle was at work, 45 minutes away from where Alex went to school. On the other end of the line was an emergency medical technician who told her, "Alex has been admitted to the hospital after being revived with CPR; he just had a life-threatening asthma attack."

Rushing to the hospital, dreadful thoughts rushed into Michelle's mind. But once she arrived at the hospital and found Alex recovering, the terrifying experience became a learning opportunity, leading Michelle and Alex to an innovative asthma program. The program, a hospital-community partnership, takes a comprehensive approach to managing asthma, including home health assessments, tailored education, and goal setting.

African Americans have the highest rates of asthma death in the United States, and Illinois has the nation's highest African American asthma death rate. Within Chicago, the asthma-related hospitalizations in the nearly 100% African American Englewood neighborhood are double the city's average. When an entire community is shouldering such a heavy burden of a complex, chronic disease like asthma, it takes more than educating families about asthma to conquer the disease; it must be a collaborative effort.

IMPROVING CHILDHOOD ASTHMA OUTCOMES: POLICY RECOMMENDATIONS UNHEEDED

Alex's aunt is the senior policy analyst for the President's Task Force on Environmental Health Risks and Safety Risks to Children. The task force was originally established in April 1997 under President Clinton by Executive Order 13045, renewed twice during President Bush's administration until 2005, and just revived in 2010 under President Obama, following the release of an evidence-based policy report entitled, Changing pO₂licy: The Elements for Improving Childhood Asthma Outcomes.¹ This policy report recommended, among other things, the creation of a Department of Health and Human Services-led, cross-agency, administration-wide national plan for changing childhood asthma outcomes and coordinating existing and new programs and policies that directly affect children with asthma. The task force, a collaborative effort, is cochaired by the secretary of the Department of Health and Human Services and the administrator of the Environmental Protection Agency and includes representatives from 16 departments and White House offices (see Box 13-1).

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- Secretary of education
- Secretary of labor
- Attorney general
- Secretary of energy
- Secretary of housing and urban development
- Secretary of agriculture
- Secretary of transportation
- Director of the Office of Management and Budget
- Chair of the Council on Environmental Quality
- Chair of the Consumer Product Safety Commission
- Assistant to the president for economic policy
- Assistant to the president for domestic policy
- Assistant to the president and director of the Office of Science and Technology Policy
- Chair of the Council of Economic Advisers
- Other officials of executive departments and agencies as the president may, from time to time, designate

The task force initially identified asthma as one of four priority areas for immediate attention. In 1999, the task force wrote *Asthma and the Environment*—*A Strategy to Protect Children* to further understand how environmental factors relate to the onset of asthma and triggers of asthma attacks.² In this strategic document, it recommended the:

- Strengthening and acceleration of focused research into the environmental factors that cause or worsen childhood asthma.
- Implementation of public health programs that improve the use of scientific knowledge to prevent and reduce the severity of asthma symptoms by reducing environmental exposures.
- Establishment of a coordinated nationwide asthma surveillance system for collecting, analyzing, and disseminating health outcome and risk factor data at the state, regional, and local levels.
- Identification of the reasons for and elimination of the disproportionate burden of asthma among dif-

ferent racial and ethnic groups and those living in poverty.

Eleven years later, the *Changing* pO₂licy report found the majority of the task force's recommendations had yet to be implemented. As a result, the administration set the task force in motion again and established a subcommittee on asthma disparities to consider the recommendations of the evidencebased policy report, particularly which ones to follow and how best to implement them. In addition, the task force considered the context set by health reform legislation passed by Congress and signed by President Obama. Enacted on March 23, 2010, the Patient Protection and Affordable Care Act called for the restructuring of health insurance markets, significant expansions of insurance coverage, and reform in provider payment and service delivery systems, and it established a number of new national pilot programs to improve performance of the health system. Many provisions of the new law had implications for the coverage of children with asthma and the performance of the system in providing high-quality care to these children, which was also raised in the report.¹

Since much had changed since 1999, the task force had to map out a new strategy. To begin, members set out to answer the following questions framed around three essential areas describing the health problem, describing possible solutions, and laying out recommendations:

- What are the key risk factors that trigger asthma and hinder proper management of the condition?
- What are the existing programs and policies that can be leveraged to improve childhood asthma treatment and management?
- What are the existing programs and policies that can be amended to improve childhood asthma treatment and management?
- What will be the impact of comprehensive health reform on existing strategies for improving childhood asthma treatment and management? What are the new opportunities presented by health reform?
- What recommendations can be made to reduce the overall burden of asthma and racial and ethnic disparities, and in particular, disparities in access to effective treatment and health outcomes?

ASTHMA IS PREVALENT AND COSTLY, YET MANY ADVERSE OUTCOMES CAN BE PREVENTED AND UNNECESSARY COSTS AVOIDED

Asthma is a chronic lung disease that affects people of all ages, but often begins in childhood. It can impose serious limitations on the normal activities of childhood and can lead to death if not treated and managed properly. However, appropriate treatment and management can control symptoms and allow those with the disease to be able to continue to enjoy healthy, active lives. According to data drawn from the National Health Interview Survey and the Medical Expenditures Panel Survey, asthma is the most common chronic condition among children. In 2008, 1 in every 7 (10.2 million) U.S. children had lifetime asthma and 1 in 11 children (6.95 million) had current asthma.³

Asthma is not only common among children, but it is costly. Asthma adds about 50 cents to every healthcare dollar spent on children with asthma compared to children without asthma. In 2006, the average total healthcare expenditures for children with asthma were \$1,906 compared to \$1,263 for children who were not diagnosed with asthma.⁴

Unfortunately, the presence of asthma is growing. The percentage of children ever being diagnosed with asthma increased from 11.4% in 1997 to 13.5% in 2006.⁵

Asthma appears to be equally prevalent in children living in rural and urban areas. However, low-income and minority children bear the heaviest burden of asthma and its consequences. One in three children living with asthma is poor, and 60% have family incomes below twice the federal poverty level.^{1,6} African American and Hispanic children receive about half as much outpatient care and medication management as white children.⁴ Death from asthma is nearly seven times higher among African American children compared to white children. Minority children have more missed days of school or work, higher rates of hospitalizations, emergency room visits, and elevated risks for mortality.⁷

An estimated 9% of all the children living with asthma remain completely uninsured.^{5,6} The evidence shows that uninsured children with asthma receive fewer office and outpatient visits, prescriptions, and preventive checkups than publicly insured children.^{5,6} Even where access exists, care may be clinically incomplete and inadequate. It has been estimated that fewer than 50% of children with asthma receive quality care.⁸

Asthma Risk: A Constellation of Factors

Asthma is the result of many factors, some of which can be controlled, some of which cannot be. Among children, certain immutable characteristics, such as gender and genetic predisposition, seem to be predictors of asthma. A history of allergies also appears to be a predictor. For children with these risk factors, paying attention to controllable risks may be especially important.

A major body of research into the effective management and treatment of asthma underscored four major risk factors that can be controlled or changed through intervention. They are:

- 1. Inadequate access to appropriate, high-quality health care and case management
- 2. A failure to address the indoor air environment and other indoor asthma triggers and outdoor environmental triggers that affect communities in which children live and grow
- 3. The absence of a means for monitoring asthma prevalence and treatment in order to effectively deploy resources at the local level
- 4. A coordinated research strategy

Inadequate Access and Case Management

Experts from the National Heart, Lung, and Blood Institute/ National Asthma Education and Prevention Program presented comprehensive recommendations on clinical practice standards that built on the best evidence. But the current national system performance standards failed to capture many of these recommended clinical standards (see Table 13-1), particularly asthma education, case management, and environmental remediation. Neither the National Heart, Lung, and Blood Institute/National Asthma Education and Prevention Program clinical practice guidelines nor the system performance measures captured providers' ability to use health information technology in practice, to exchange data with other clinical providers and healthcare entities, to exchange data with school systems and other community programs serving children with asthma, or to report treatment and management data to payers or public health agencies. None of the available measures could assess the effectiveness of reporting from ambulatory care settings into a public health registry or the effectiveness of reporting between a public health registry and payers.

A Failure to Address the Environment and Asthma Triggers

The data showed exposure to cigarette smoke, other irritants (such as strong odors and nitrogen dioxide), and certain indoor allergens (dust mites, pets, cockroaches) increase children's risk of developing or losing control of asthma.

The Absence of a Means for Monitoring Asthma Prevalence and Treatment

An effective system has never existed for monitoring the prevalence of asthma at the national, state, and community levels and for gauging the availability of effectiveness of treatment and its outcome on child health. A systematic approach

	Clinical Standards	Performance Measures	
Asthma Categories	NAEPP EPR3 Guidelines for the Diagnosis & Management of Asthma	National Quality Forum Measures	CHIPRA Children's Health Quality Core Measures, AHRQ
Asthma Measurement	Yes	Yes ¹	No
Asthma Management: Asthma Education	Yes	No	No
Written Action Plans	Yes	Yes ^{2,3}	Yes ^{4,5}
Case Management	Yes	No	No
Management of Co-morbid Conditions	Yes	No	Yes ⁶
Environmental Remediation	Yes	No	No
Appropriate Medication	Yes	Yes ^{7–10}	Yes ¹¹⁻¹³
Hospitalizations & Use of ED	No	Yes ¹⁴	Yes ^{15,16}

TABLE 13-1 Recommended Clinical Standards Compared to Performance Measures for Asthma¹

¹ Asthma Assessment—Percentage of patients who were evaluated during at least one office visit for the frequency (numeric) of daytime and nocturnal asthma symptoms

 2 Management plan for people with asthma—Percentage of patients for whom there is documentation that a written management plan was provided either to the patient or the patient's caregiver or at a minimum, specific written instructions on under what conditions the patient's doctor should be contacted or the patient should go to the emergency room

³ Home Management Plan of Care Document Given to Patient/Caregiver—Documentation exists that the Home Management Plan of Care (HMPC) as a separate document, specific to the patient, was given to the patient/caregiver, prior to or upon discharge.

⁴ From 3rd round of measures that did not meet thresholds for Delphi II scoring, CHIPRA Children's Healthcare Quality Measures, AHRQ: Percentage of patients for whom there is documentation of a written asthma action management plan was provided either to the patient or the patient's caregiver OR, at a minimum, specific written instructions on under what conditions the patient's doctor should be contacted or the patient should go to the emergency room ⁵ AHRQ. Joint Commission only measure: Children's asthma care: percent of pediatric asthma inpatients with documentation that they or their caregivers were given a Home Management Plan of Care (HMPC) document

⁶ From 2nd round of measures that passed Delphi II but not recommended, CHIPRA Children's Healthcare Quality Measures, AHRQ: Annual influenza vaccination (all children and adolescents diagnosed with asthma)

⁷ Suboptimal Asthma Control (SAC) and Absence of Controller Therapy (ACT)—Rate 1: The percentage of patients with persistent asthma who were dispensed more than 5 canisters of a short-acting beta2 agonist inhaler during the same three-month period. Rate 2: The percentage of patients with persistent asthma during the measurement year who were dispensed more than five canisters of short-acting beta2 agonist inhalers over a 90 day period and who did not receive controller therapy during the same 90-day period.

⁸ Use of Appropriate Medications for People with Asthma—Percent of patients who were identified as having persistent asthma during the measurement year and the year prior to the measurement year and who were dispensed a prescription for either an inhaled corticosteroid or acceptable alternative medication during the measurement year

⁹ Asthma Pharmacologic Therapy—Percent of all patients with mild, moderate, or severe persistent asthma who were prescribed either the preferred long-term control medication (inhaled corticosteroid) or an acceptable alternative

¹⁰ Use of Systemic Corticosteroids for Inpatient Asthma—Percentage of pediatric asthma inpatients (age 2–17 years) who were discharged with principle diagnosis of asthma who received systemic corticosteroids for inpatient asthma.

¹¹ From 2nd round of measures that passed Delphi II but not recommended, CHIPRA Children's Healthcare Quality Measures, AHRQ: Use of appropriate medications for people 5–20 years of age with Asthma-Average number of member controller months

¹² AHRQ, Joint Commission only measure: Children's asthma care: percent of pediatric inpatients who receive systemic corticosteroids during hospitalizations

¹³ AHRQ, Joint Commission only measure: Children's asthma care: percent of pediatric asthma inpatients who received relievers during hospitalization ¹⁴ Use of Relievers for Inpatient Asthma—Percentage of pediatric asthma inpatients, age 2–17, who were discharged with a principal diagnosis of asthma who received relievers for inpatient asthma

¹⁵ Annual number of asthma patients (> 1 year old) with > 1 asthma-related ER visit

¹⁶ From 2nd round of measures that passed Delphi II but not recommended, CHIPRA Children's Healthcare Quality Measures, AHRQ: Annual number of asthma patients (> 1 year old) with > 1 asthma-related hospitalization

Source: Markus A, Lyon M, Rosenbaum S. Changing pO₂licy: The Elements for Improving Childhood Asthma Outcomes. Washington, DC: The George Washington University School of Public Health and Health Services. http://www.mcanonline.org/policy_issues/index.html. Revised March 10, 2010. Accessed November 1, 2010.

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to asthma monitoring that captured asthma prevalence information was also absent.

A Coordinated Research Strategy

Despite the disproportionately large number of funded asthma studies and numerous agencies involved in asthma research, there was no single unified research agenda, though, as of 2010, research and policy initiatives that address childhood asthma existed at Health and Human Services, Department of Housing and Urban Development (HUD), Environmental Protection Agency, and the Department of Education.

Childhood asthma is a serious and chronic health issue that affects many U.S. children like Alex and their families, compromising their health and quality of life and placing a heavy financial burden on families as well as an enormous strain on the healthcare system. Treating, managing, and ultimately preventing and reducing the burden of asthma represents a critical test of the ability of the U.S. health system health insurers, clinical care providers, and public health agencies—to work together.

TURNING KNOWLEDGE INTO STRATEGY

From the evidence base of in-depth research into the effective management and treatment of asthma, the task force knew the factors that could be controlled or changed through intervention.

At a minimum, elements for improving childhood asthma outcomes included the following:

- Stable and continuous health insurance
- High-quality clinical care, case management, and asthma education available for all children, including those who remain ineligible for insurance coverage
- Ability to continuously exchange information and monitor progress, using as much health information technology as possible
- Reduction of asthma triggers in homes and communities
- · Learning what works and increasing knowledge

Since asthma is disproportionately concentrated among lower income children, Medicaid and the Children's Health Insurance Program were particularly key. As of 2009, 29 million children were enrolled in Medicaid and 7 million in the Children's Health Insurance Program. The Children's Health Insurance Program Reauthorization Act of 2009 provided enhanced funding to permit coverage of children in families with incomes up to 300% of the federal poverty level, while providing federal assistance at regular Medicaid matching rates in states that elect to extend coverage still further. Of this number, an estimated 180,000 would be previously uninsured children with asthma. The Children's Health Insurance Program Reauthorization Act allowed states to reach all financially eligible, legally resident children during the first 5 years of their U.S. residency. The Children's Health Insurance Program Reauthorization Act further simplified citizenship documentation requirements and provided bonus payments to states whose enrollment and retention efforts produced enrollment levels that exceeded their target rates. Full implementation of these reforms could help reach the nearly 600,000 children with asthma who were eligible for coverage in 2010 but remained unenrolled. The reauthorization also provided \$100 million in outreach funds, established a multiyear clinical quality improvement initiative, and contained demonstration funding to improve the use of health information technology.9

The quality of the clinical care available to children with asthma is critical. In Fall 2010, the elements of recommended clinical practice in the case of pediatric asthma based on the latest National Heart, Lung, and Blood Institute/National Asthma Education and Prevention Program guidelines boiled down to a key imperative: a medical home with skilled and knowledgeable healthcare professionals who, acting as a team, continuously monitored a child's health status over time and managed the medications crucial to improved long-term lung function (not merely episodic management of attacks).^{10,11} Furthermore, healthcare professionals had to be able to effectively communicate to children and families at an appropriate literacy level (including having easily comprehensible health education materials and written asthma action plans), so that families were armed with the knowledge and information they need to reduce risks and manage their children's condition. In addition to effective communication with families, health professionals had to be able to communicate with each other in the treatment and management of asthma, through the appropriate and efficient use of health information technology.

Some families whose children had asthma were able to put knowledge into practice on their own. Other families, whose children might be at the highest risk, also faced added barriers of poverty, family stress, and other factors that could limit their ability to turn knowledge into action. For these families, the healthcare system needed to be able to support them outside of the office practice and in community settings through home visits and case management supports.

Knowing which communities experience a particularly great burden of asthma and the number of children receiving effective treatment, tracking serious incidents, such as the hospitalization or death of a child from asthma, and having the information needed to deploy community prevention resources are the hallmarks of an effective and engaged public health system. An additional critical role for public health is translating evidence into information regarding asthma's prevalence and impact in order to provide the evidence base for community-wide interventions aimed at reducing environmental risks, such as vehicle emissions (including idling around schools), pesticide control, environmental tobacco smoke, and pest management for housing units. With nationwide adoption of such a registry system would come far better knowledge about the prevalence of asthma and the quality of treatment.

Because asthma can be initially triggered or retriggered by many environmental factors, their removal from a child's home environment is essential.¹² Seminal National Institutes of Health–funded, multisite, randomized, controlled, intervention research studies published in the late 1990s and early 2000s^{13–20} yielded important insight into the role of integrated pest management and other cleaning strategies to reduce triggers and control asthma symptoms in the home. A growing body of evidence suggested that interventions designed to improve the environments where children played and lived could help decrease asthma morbidity.^{13–20}

UPDATING THE NATIONAL STRATEGY

With this information in hand, task force members were faced with updating their strategy. The senior policy analyst on the task force reflected on how effective her nephew's comprehensive hospital-community asthma management program was in helping him to gain and keep control of his asthma. She was able to describe to the members that the program consisted of the following:

- Case management (by nurses) for children with excessive absences and/or emergency department use; children are linked with asthma care provider either through free clinic or asthma-mobile
- Children in case management assisted in enrolling in state insurance program
- Collaboration with partners to deliver provider education
- Enforcement of self-management skills for children and improvement of knowledge amongst school staff
- Work to promote asthma management activities in other school districts
- Pilot age-appropriate asthma curricula aligned with health education standards for the state in elementary/middle/ high schools
- Implementation of tools for schools and education about the state's integrated pest management service
- Participation and attendance at local asthma coalition meetings and events and presentations and dissemination of educational materials at local health fairs

- In-home assessments, education and environmental mitigation by nurse case managers, distribution of mattress/ pillow covers and referrals for other services (smoking cessation, low interest home improvement loans)
- Collaborations with community and government agencies to educate about safe indoor air quality
- Establishment of a case-management tracking system that captures ethnic and socioeconomic status information and other data such as emergency room visits and days of school missed
- Identification of culturally and linguistically appropriate asthma materials

In order to produce their strategic document, task force members needed to answer the following key questions:

- What are the key risk factors that trigger asthma and hinder proper management of the condition today?
- What are the existing programs that can be used or amended to improve childhood asthma treatment and management?
- What policies can be developed to facilitate the implementation of these existing programs?
- What has been the impact of comprehensive health reform so far on existing strategies for improving childhood asthma treatment and management, and what are new opportunities presented by other recent reforms?
- What recommendations can be made to reduce the overall burden of asthma and racial and ethnic disparities—in particular, pertaining to access to effective treatment and health outcomes?

About the Authors

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Shavon Artis, MPH, is a doctor of public health candidate in the Department of Health Policy at The George Washington University. She has 10 years of experience in developing and implementing health promotion/disease prevention programs. She has developed and conducted health programs to improve the health of women, children, and minority communities, developed culturally tailored health education materials for national health promotion programs, developed and conducted training workshops for communities and health professionals, and has produced health policy reports for senior government health officials. In her current position as a public health analyst at the Eunice Kennedy Shriver National Institute of Child Health and Human Development at the National Institutes of Health in Bethesda, Maryland, she oversees and directs the Back to Sleep campaign, a national outreach effort to reduce infant deaths from sudden infant death syndrome. She is responsible for carrying out a plan for building strategic partnerships and conducting focused outreach to promote the campaign and other health initiatives across the country.

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