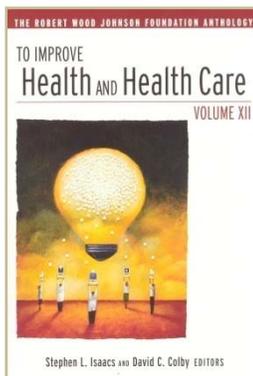




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Chapter Nine,
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Editors' Introduction

With few exceptions, the Robert Wood Johnson Foundation does not fund programs that concentrate on specific diseases. It made an important exception in the 1980s with its programs to address what was then a nascent AIDS epidemic. This came at a time when few foundations were willing to address HIV/AIDS, and it thrust the Foundation into such a leadership role that David Rogers, the Foundation's first president, was named vice chairman of the National AIDS Commission upon his retirement.

The only other time that the Foundation adopted a disease-specific approach occurred a decade later, when it initiated programs to address depression, diabetes, and childhood asthma. Although these programs were justified in part because of the serious health consequences of these conditions, the primary justification was the potential for discovering approaches to these diseases that could be applied to chronic illnesses across the board. By contrast, the Foundation had been supporting a more general approach to chronic illness, the "chronic care model" pioneered by Edward Wagner, a physician at the Group Health Cooperative in Washington state (it should be noted that, in practice, projects undertaken under the more general chronic care approach often focused on a single disease such as asthma or diabetes).¹

In this chapter, Alexis Levy, a communications associate at the Foundation, reports on the development and execution of the Foundation's efforts to reduce childhood asthma. To do this, the Foundation funded a broad interlocking series of programs to address asthma from various perspectives. Designed to complement the pediatric asthma work carried out by the federal government and by nongovernmental organizations, the perspectives included a policy component, a coalition-building component, a curriculum development component, a financing component, and a component to improve the treatment of patients going to emergency departments to treat an asthma attack.

As Levy notes, the Foundation's disease-specific approach was short lived; the asthma initiatives were not expected to be re-funded, and they were not. Asthma prevention and management, however, can still be supported under the Foundation's current priorities, such as improving quality and equality of care and protecting vulnerable populations. Despite their short life, a considerable amount was learned from the series of programs about managing asthma—even as the prevalence of the illness and its toll on health continues to grow. And although the series of programs did not have a significant effect on the

management of other chronic conditions, it has provided support for the use of community coalitions, self-management, and community-based primary care, plus what the Foundation-funded RAND report termed “an investment . . . into the realm of behavioral and lifestyle modification, educational services, housing, environmental reforms, and other community services”²—all of which are now considered standard, albeit challenging, approaches in addressing chronic conditions caused by multiple factors.

Notes

1. See Wielawski, I. M. “Improving Chronic Illness Care.” *To Improve Health and Health Care: The Robert Wood Johnson Foundation Anthology*, Vol. X. San Francisco: Jossey-Bass, 2006.
2. Lara, M. and others. “Improving Childhood Asthma Outcomes in the United States: A Blueprint for Policy Action.” *Pediatrics*, 2002, 109, 919–930.

The Robert Wood Johnson Foundation has a long history of working to improve clinical care for people with chronic health conditions, although, for the most part, the Foundation has avoided concentrating on specific illnesses. In 1991, the Foundation designated chronic care as one of three priority areas and funded approaches that would improve the care of people with *any* chronic condition. Seven years later, an internal working group, organized to consider how the Foundation might focus its efforts to improve the care of people with chronic illnesses, recommended that the Foundation supplement its programs to improve the prevention and management of chronic illness as a whole by concentrating on a few specific chronic diseases. The working group, whose recommendations were adopted by the Foundation, reasoned that in addition to benefiting people with the disease, an illness-specific approach might lead to the development of models of care that could be applied to other chronic conditions.

Pediatric asthma seemed like an obvious choice as a chronic disease on which to focus. It was widespread, had serious health (as well as financial) consequences, and disproportionately affected poor children. Moreover, the management of childhood asthma was falling well short of the goals established by the National Heart, Lung, and Blood Institute for asthma care, largely because of poor communication between patients and providers and the failure of patients and their families to comply with self-management regimens. These considerations led the Foundation to name pediatric asthma as the first of the chronic illnesses on which it would concentrate. The two others were depression and diabetes.

Asthma and Its Consequences

Asthma is a chronic respiratory disease characterized by inflammation and narrowing of the airways that carry air in and out of the lungs. During an asthma attack, these airways narrow as the muscles around them tighten and the inflammation of their walls increases, limiting the flow of air into the lung tissue and causing shortness of breath, coughing, wheezing, and tightness in the chest or chest pain. Asthma attacks can range from mild to life-threatening.

Asthma affects approximately 22 million Americans, of whom nearly 7 million are children. It is the most common long-term disease of children in the United States.¹ African Americans are at a higher risk of asthma than any other racial or ethnic group. In fact, the prevalence rate of asthma in African Americans is almost 36 percent higher than the rate among whites.²

Although the causes of asthma are still not well understood, it is widely believed that family history plays a role. It is also widely accepted that certain environmental triggers can lead to an asthma attack, including allergens such as animal dander, dust mites, pollen, and mold; irritants like cigarette smoke, scented products, air pollution, and stress; and viral infections.

The methods used to control asthma typically include the use of medication and the avoidance of triggers. Medications to treat asthma are typically inhaled directly into the lungs and fall into two categories: quick-relief and long-term control. Quick-relief medications are used to provide immediate relief from the symptoms associated with an asthma attack, whereas long-term control medicines are taken on a regular basis to reduce the frequency and intensity of attacks.

Not only is asthma the most common long-term disease affecting American children, it is the third leading cause of hospitalizations for children seventeen years of age and younger, exceeded only by pneumonia and injuries. And although asthma deaths among children are rare, they do occur; 141 children under the age of fifteen died as a result of asthma in 2004.³ Moreover, asthma attacks can interfere with a child's ability to perform everyday activities, such as attending school. The illness accounts for nearly 15 million missed school days annually.⁴ And there are also, of course, significant financial implications associated with this disease. According to the Centers for Disease Control and Prevention (CDC), it costs approximately \$3.2 billion to treat pediatric asthma in the United States each year.⁵ This is clearly a serious disease, with serious implications.

The Foundation's Approach to Childhood Asthma

The Foundation's staff viewed pediatric asthma as an example of a specific disease that crosses many systems and populations and saw an opportunity to address various components of the health care system by focusing on this single disease. A 1999 staff paper included the following justification for the Foundation's entering the pediatric asthma field:

- The benefit of utilizing existing models of care that can be adapted from treatment of adult asthma
- A strong research base and continued funding for basic -biomedical research from the National Institutes of Health as well as leverage from private industry, including the pharmaceutical world
- The growing community-based support and acknowledgement by the public and health care providers of the seriousness of this chronic illness

- The relatively short time for positive outcomes and return on investment compared to other chronic illnesses or behavior change programs
- The ability to document discrete changes in health outcomes relative to other chronic illnesses or programs supported by the Foundation
- The synergy between programming opportunities in pediatric asthma management and other programs currently supported by the Foundation
- The opportunity based on the above characteristics to utilize pediatric asthma management as a model for other chronic illnesses that the Foundation may study

This perspective led the Foundation to take a wide-ranging approach, and it developed an initiative with six related components, each focusing on a different aspect of improving pediatric asthma treatment and management: addressing policy issues, training providers, examining barriers to financing and treatment, supporting community-based approaches to pediatric asthma management, testing new methods of providing emergency department-based care, and testing models of treating high-risk children in Medicaid managed care settings. Three of these six components were national programs, and the other three were located at a single site.

The three national programs were the following:

- **Allies Against Asthma: A Program to Combine Clinical and Public Health Approaches to Chronic Illness.** This eight-year, \$12.5 million program, housed at the University of Michigan School of Public Health's Center for Managing Chronic Disease, supported seven local coalitions and their efforts to improve the prevention and management of asthma in their communities. This program was built on a belief within the Foundation that local coalitions were an effective way of combating social and health issues in the community.⁶
- **Improving Asthma Care for Children.** This \$3.25 million program, housed at the Center for Health Care Strategies, whose offices are currently located in Hamilton, New Jersey, tested innovative approaches to managing asthma in children receiving care in five Medicaid managed care settings.
- **Managing Pediatric Asthma: Emergency Department Demonstration Program.** This component attempted to find ways in which emergency physicians and nurses could educate and assist patients and their parents to better manage the illness and to direct them to community resources that could help them prevent or manage future attacks. The American Academy of Allergy, Asthma & Immunology served as the National Program Office for this six-year, \$3.5 million project that took place at four locations.

The three single-site projects were the following:

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- Policy Options to Improve Pediatric Asthma Outcomes in the United States. The policy component was carried out by the RAND Corporation, which received a grant of \$228,000 from the Foundation to develop a Blueprint for Policy Action calling for the creation of “asthma-friendly” communities, that is, communities in which children with asthma are diagnosed quickly and receive appropriate treatment; health care facilities, schools, and social agencies are equipped to meet the needs of children with asthma and their families; and children are safe from the physical, social and environment risks that exacerbate asthma.
 - Physician Asthma Care Education. To improve the capacity of physicians to recognize and treat asthma, the Foundation awarded \$2.4 million to the University of Michigan School of Public Health to develop the Physician Asthma Care Education project, a multifaceted educational program to improve physician awareness, attitudes, ability, and the application of communication and therapeutic skills for asthma.
 - Exploring Barriers to Financing and Treating Pediatric Asthma. The Center for Health Care Strategies received \$500,000 to identify limits on financing and treatment for pediatric asthma and to disseminate its findings by means of a conference and publications.

Allies Against Asthma

Allies Against Asthma, the largest of the Foundation’s pediatric asthma programs, was launched in 1999 to support community-based coalitions in developing and carrying out comprehensive pediatric asthma management programs. The primary aims of the program were to (1) reduce hospital admissions, emergency room visits, and missed school days; (2) enhance the quality of life for children with asthma; and (3) develop a sustainable strategy for asthma management in communities.

Shortly after establishing the Allies National Program Office at the University of Michigan School of Public Health and naming a fifteen-member national advisory committee made up of asthma experts from various disciplines, the Foundation began the process of selecting the coalitions. In the call for proposals, potential applicants were given the challenge of developing and implementing a community action plan—one that reflected the needs and resources available in their own community—to improve the prevention and management of pediatric asthma. Of the more than 250 coalitions submitting proposals, seven were selected to participate in the program:

- Alianza Contra el Asthma Pediátrica en Puerto Rico, a coalition in San Juan, Puerto Rico, centered on an eighty-three-acre San Juan housing project whose 8,800 residents include 600 children with asthma
- The Consortium for Infant and Child Health, which was established in 1993 to address concerns about childhood immunization rates in Hampton Roads, Virginia, and the surrounding region. The organization’s role expanded to address childhood asthma, estimated to affect one of every ten children in the region.

- The National Capital Asthma Coalition, a Washington, D.C.–based coalition that aimed at reducing pediatric asthma-related hospitalizations, emergency department visits, and school absences for children with asthma living in five predominantly African American and Hispanic areas of the city where pediatric asthma hospital discharges are high
- Fight Asthma Milwaukee Allies, which grew out of the existing Fight Asthma Milwaukee coalition, established in 1994 by a group of volunteers working to conduct asthma surveillance among African American children
- The King County Asthma Forum, established in 1998 in King County, Washington, by the American Lung Association of Washington and the local public health department. The Forum targeted low-income children in central and south Seattle and southwest King County, where the pediatric asthma hospitalization rate had increased 62 percent from 1988 to 1995.
- The Long Beach Alliance for Children with Asthma, whose efforts are primarily directed toward Latino children in the city of Long Beach, California, an estimated 15 percent of whom have asthma
- The Philadelphia Allies Against Asthma Coalition, which focused on reducing asthma-related morbidity in North and West Philadelphia, home to more than 14,000 children with asthma

Each coalition received a one-year planning grant of \$150,000 in 2001. After the planning period, the coalitions received implementation grants of up to \$1.35 million each to support their efforts, which were completed by December 2006. The sites were also expected to secure matching funds totaling one-third of each year’s budgeted support from the Robert Wood Johnson Foundation.

Coalitions have long been used as a means to address community health issues. According to Noreen Clark, former dean of the University of Michigan School of Public Health and the program director of Allies Against Asthma, there are currently more than two hundred such coalitions devoted to asthma prevention and management in the United States. One reason that pediatric asthma lends itself so well to coalitions is that it takes a wide variety of interventions to address the disease—medical, environmental, social, and political—and these interventions can be done more effectively in a collaborative setting. Clark notes that “Allies Against Asthma sought to bring together parents and caregivers of children with asthma, medical providers, insurers, public health and environment agencies, housing professionals, schools, community organizations, local officials, business and industry, and grassroots advocacy groups to develop and implement innovative approaches to improve care and coordinate efforts across organizations and agencies.”⁷

A Panorama of Activities Carried Out by the Allies Against Asthma Coalitions
Although each coalition addressed the specific needs identified by its members, their activities tended to fall into one or more of the following approaches:⁸

- ***Health care provider education:*** Almost all of the sites provided training for physicians based on the Physician Asthma Care Education program, which was developed by the University of Michigan School of Public Health under a separate grant from the Foundation. The Physician Asthma Care Education program is designed to improve physician awareness, attitudes, and skills relating to asthma management and to enhance physicians' communication with patients regarding self-care for asthma. The program includes training seminars, an educational tool kit, and an educational Web site. The National Heart, Lung, and Blood Institute has also begun to distribute materials from the program in order to ensure their widespread dissemination.

In addition to the Physician Asthma Care Education program, many coalitions developed their own provider training and education programs. The Fight Asthma Milwaukee Allies coalition, for example, developed several programs for this purpose, such as Teach Asthma Management, a workshop that provides guidelines on asthma care for nurses, clinic staff, and health educators and demonstrates teaching techniques and communications methods they can use to assist families in improving self-management.

- ***Managing pediatric asthma at home:*** The Consortium for Infant and Child Health in Hampton Roads, Virginia, initiated a series of Asthma Housing Summits, a three-part program designed to decrease environmental asthma triggers in public housing through education for Housing Authority management and residents. Its Ambassador Program, in which individuals from local communities were trained as "health ambassadors" and provided local families with education about asthma triggers and asthma management during a series of home visits, not only helped children suffering from asthma but also changed the lives of some of the health ambassadors themselves. Two such ambassadors, Xina Opie and Natasha Perkins, were known in the communities they served as "the asthma ladies." Both grew to love the program, even after it ended, and are continuing to work as ambassadors for other programs, and both decided, on the basis of their work for the Consortium, to go back to school: Opie has completed her associate's degree and is now a certified nursing assistant, and Perkins is currently pursuing a degree in social work and is returning to school to earn a nursing degree.
- ***School and childcare center-based programs:*** Most of the programs gave some attention to the places where children spend their day. The Long Beach Alliance for Children with Asthma, for example, trained school nurses to recognize asthma, manage its symptoms, and deliver medication when needed, and it provided similar kinds of training for front-line staff workers at after-school programs, Head Start, and other childcare sites.
- ***Community and clinic-based programs:*** Many coalitions sponsored activities within their communities and local clinics. The Philadelphia Allies Against Asthma Coalition, for example, established several community and clinic-based programs, among them Smokeless Homes, through which coalition members made presentations about and discussed with community members the dangers of smoke pollution within the home and helped them find

smoking-cessation programs, and the All About Asthma Workshop, a general asthma educational presentation conducted in both English and Spanish for parents and caregivers.

- **Policy and advocacy:** Among the policy activities carried out under the program, the King County Asthma Forum worked in partnership with the American Lung Association of Washington and the Washington State Asthma Initiative state asthma coalition to educate policymakers about the importance of having a policy that would allow elementary and secondary school students to bring asthma medications to school.

Two Allies Sites in Action

Philadelphia Allies Against Asthma

The Child Asthma Link Line program of the Philadelphia Allies Against Asthma Coalition illustrates the kinds of work that the coalitions are doing. To link families to Philadelphia’s existing resources, Philadelphia Allies’ coalition members created a free telephone hotline, the Child Asthma Link Line. Michael Rosenthal, a practicing physician and professor of family and community medicine at Thomas Jefferson University and co-chair of Philadelphia Allies, explains that the Link Line was developed to be much more than just a telephone hotline—it really serves as an “interactive and supportive service to help kids and their families get care and support services” in a system that can, at times, be a bit difficult to navigate. As Rosenthal says, it literally “links” people. Collaboration among Philadelphia’s three Medicaid managed care organizations—Keystone Mercy Health Plan, Health Partners, and AmeriChoice of Pennsylvania—has been crucial to making the Link Line work.

Families receiving services through the Link Line are identified through brief questionnaires that are made available through a network of community-based organizations, health care providers, schools, and government agencies (since 2002, the Link Line has received 2,900 referrals from ninety-five different referral sources). When somebody sends a filled-in questionnaire to the Link Line, it will probably be seen first by Marla Vega or Barbara Washington. Vega, who has a master’s degree in education, was employed as a teacher when she first received supportive services for her developmentally disabled daughter from the Philadelphia Health Management Corporation (now the Public Health Management Corporation), a nonprofit health organization in which the Link Line is housed. She was so impressed with the kind of help that she and her daughter received that she decided to help others the same way. In 2002, Vega became a Link Line coordinator. Washington, another Link Line coordinator, also began her work with the Link Line in 2002. She has spent the past thirty years working in the areas of social service, education, and health education.

Once Vega and Washington receive the completed questionnaires, they enter the information into a database filled with more than 2,800 names and then begin the process of reaching out to the families. Vega deals with most of the Spanish-speaking families since she is bilingual. However, because of the volume of completed questionnaires they receive, both women help English-speaking families and also families whose primary language is something other than English or Spanish.

During the first call with a family, Vega and Washington ask a series of questions to gain a better understanding of the family's situation. As they listen to the answers, the women make notes regarding topics they need to address with the families, such as medication management, triggers in the home, and the importance of regular doctor visits. In some cases, they will end up talking about the fundamentals of pediatric asthma and steps that can be taken to help manage it—not smoking in the home, for example, and keeping high-allergy pets, such as cats, out of the bedroom of the child with asthma. They never scold a family for having these triggers or suggest that they take drastic steps to eradicate them, like getting rid of their family pet. They simply suggest small, manageable steps the family can take right away to improve the situation and then provide the parents with information that may be useful to them in the future, such as, in the case of smokers, the names of community-based cessation programs.

In other cases, they may try to connect families with resources in their communities or provide them with information and tools so that they are more able to deal with their doctors and schools. One of the questions Vega and Washington always ask during an introductory call pertains to how many inhalers the children have. If the answer is only one, they will inform the parents that they have the right to request two—one for home and the other for school—and tell them what they need to do to make this request of their physician.

On many calls, the coordinators uncover other issues affecting the family. They may direct parents to non-health-related social services, such as programs to help parents get high school diplomas, legal advice, or services that provide housing or job support. The Link Line counselors, in other words, take a holistic approach to the needs of families and children with asthma. “We have built a relationship with families that goes beyond providing resources,” Washington says. “We provide moral support. We empower people. The whole program has increased the community's expectations. Families now see services for children with asthma as a right rather than as a nice idea.”

The Long Beach (California) Alliance for Children with Asthma

When the staff members of the Long Beach Alliance for Children with Asthma (LBACA) talk about their experiences working with the Allies Against Asthma program, one thing becomes exceptionally clear: this is a group of driven individuals. These are the people directly responsible for bringing the services of LBACA to the Long Beach community. They visit families in their homes, provide education about asthma to those who need it, help families develop asthma action plans to guide their daily management of asthma, and even attend doctor visits with families when needed. They are a much-relied-on resource for many in their community.

One of the major issues faced by Long Beach families affected by pediatric asthma is the inability to communicate effectively with health care providers. Some 44 percent of Long Beach residents over the age of five live in a household in which a language other than English is spoken in the home, making language barriers a common problem. Because of these barriers, many parents of children with asthma never fully understand the disease and the implications that its diagnosis may have for their children, including the importance of properly monitoring and managing it. And those who do understand often run into problems managing asthma because, due to miscommunications with their doctors or pharmacists, they have trouble understanding the correct way to administer prescribed medications and end up either administering them incorrectly or not administering them at all. And there are still others who avoid visits to their doctor altogether, because of the discomfort they feel during physician-patient interactions.

Home visits by community workers (*promotoras*) are one of the ways that LBACA helps families manage their children's asthma. By teaching families what asthma is, what the prescribed medications do and how to properly administer them, and how to manage asthma in the home by avoiding and eradicating environmental triggers, the staff at LBACA is able to help families be more in control. Promotora Maria Garcia recalls being referred to the home of a twelve-year-old boy who, despite taking his asthma medications, was symptomatic almost every day and needed to inhale albuterol (a medicine used to clear the lungs and airways during an asthma attack). In the home, Garcia found multiple triggers: roaches, scented oils, a cat, and dust from a backyard woodshop. She got in touch with the child's doctor and provided the entire family with asthma education and tips for reducing triggers at home. "Today the child's symptoms are reduced to almost nothing," Garcia says. "It's a great feeling when people thank you

for pointing things out to them and say, ‘Thanks to you, my son is better.’ We tell families, ‘You control asthma so asthma does not control you.’”⁹

Other Approaches to Combating Pediatric Asthma

In addition to Allies Against Asthma, the Foundation funded other, complementary programs. Under the Physician Asthma Care Education project, the University of Michigan School of Public Health developed materials for physicians on the prevention and treatment of asthma. Two others focused on finding ways to manage asthma in children in specific circumstances—Medicaid managed care plans and emergency departments—while another two supported research aimed at bringing about policy change.

Improving Management of Asthma in Medicaid Managed Care Programs

The Improving Asthma Care for Children program attempted to improve the management of asthma in children receiving health care through Medicaid managed care plans and sometimes paid for through the State Children’s Health Insurance Program (SCHIP). Providing services to these children can sometimes be a challenge, since low-income families may move frequently, may not always have telephone service, and may go on and off Medicaid due to fluctuations in family income. The five demonstration sites chosen to participate in the program were charged with developing “innovative models of pediatric asthma care for a managed care population of at least 20,000 Medicaid or SCHIP enrollees.”

Working under the overall direction of the Center for Health Care Strategies, each site took a somewhat different tack toward improving their asthma prevention and management services, though they all had certain basic elements in place. In some way, all of the projects worked to improve or develop new models for asthma care; increase coordination among providers of asthma services; provide children and their parents with education about the disease, self-management training, and in-home environmental inspections; provide training for physicians; and implement campaigns to educate schoolteachers, parents, and the general public about asthma and methods for decreasing triggers. The major activities of each of the grantees are summarized below:¹⁰

- The Affinity Health Plan in the Bronx, New York, focused its efforts on identifying new members with asthma, providing self-management education to members, and promoting adherence to national guidelines for asthma care. It developed and distributed a health assessment form to all of its new members to identify those who had asthma. By the end of the project, Affinity had identified between 300 and 400 new child members with asthma per quarter, with more than half of those identifications resulting from the project’s outreach effort. Additionally, Affinity provided home visits to members with persistent asthma. It also

developed an asthma education curriculum for physicians and routinely sent asthma performance measures to them and/or health center medical directors. At the end of the project, Affinity found that asthmatic children who received case management scored better on standard quality measures for asthma care than those who did not receive case management, that asthma-related emergency room visits dropped by more than 400 percent, and that the pediatric asthma initiative -resulted in substantial cost savings for Affinity.

- Contra Costa Health Plan, in Martinez, California, sought to improve medical management of children with asthma; reduce children's exposure to potential asthma triggers; improve communications among parents, health care providers, and educators; and gather better data on patients with asthma. The plan ultimately developed an asthma registry to track patients with asthma and initiated a community education program in the portion of the county with the highest asthma-related hospitalization rates to visit homes and educate families about eradicating triggers and managing their asthma. This project was co-funded by The California Endowment.
- Family Health Partners in Kansas City, Missouri, focused on tracking patient information through the development of a centralized asthma registry, a standardized asthma curriculum for providers and their staffs, and a community asthma outreach program. As part of its provider education efforts, Family Health Partners used certified educators to teach providers about patient education and developed a training CD-ROM for providers to use with new staff. Family Health Partners saw reductions in asthma-related emergency room visits of 45 percent, asthma-related hospitalizations of 50 percent, and asthma-related treatment costs of 35 percent.
- HealthNow NY, Independent Health Association, and Univera Healthcare, all in Buffalo, New York, worked together to improve the collection of outcome data on members with pediatric asthma. Together the plans conducted focus groups and interviews with providers and families to obtain information used in developing asthma-education tools and a public relations campaign aimed at improving asthma care; promoted community and school-based educational programs; and developed and distributed pediatric asthma practice guidelines to all primary care physicians in the region.
- The Monroe Plan for Medical Care, in Rochester, New York, focused on implementing a specialized management program for a subset of patients with moderate to severe asthma, which included services to schedule appointments for these patients with asthma center specialists, reminders about appointments, and the facilitation of transportation to appointments. Additionally, Monroe conducted home visits with members to assess and suggest remedies for triggers, educated providers, and raised public awareness. As a result of these efforts, Monroe reported that the number of moderate to severe asthma patients receiving asthma specialty services increased from 8 percent to 39 percent and the percentage of participants categorized as moderate to severe asthmatics declined from 51 percent to 26 percent by the program's conclusion.

Although the sites demonstrated varying levels of effectiveness, they all reported improvement in at least one area of childhood asthma management. On the whole, the program demonstrated that by focusing

on early detection and intervention, setting up patient registries, using a variety of outreach methods, educating providers on patient self-management, and offering incentives to providers to reward high-quality care, Medicaid managed care organizations can develop programs that improve the health of children with asthma and that save money for the health plan.

Reducing Emergency Room Visits

The Managing Pediatric Asthma: Emergency Department Demonstration Program sought to reduce visits to hospital emergency departments by tracking children who came to an emergency department suffering from asthma, educating them and their families about how to manage the disease themselves, and directing them to primary care facilities in the community. Four sites were selected to participate in the program:

- The Hawaii CARES project tracked emergency department asthma patients, provided emergency department-based education for pediatric patients and families, and offered asthma education for emergency department staff and community-based health care providers. The four medical institutes participating in the project reported that after the interventions were delivered, the use of medications to control asthma increased as did the number of children with written asthma action plans.
- The Texas Emergency Department Asthma Surveillance partnership in Houston included four hospitals and focused on recording all pediatric asthma-related emergency department visits in a database; delivering an education presentation to emergency department physicians at all four hospitals every six months; creating a computer-based tool to help asthma educators teach self-management to families; giving families asthma action plans; and getting in touch with families by phone within two weeks of an emergency department visit to reinforce the action plan and answer any questions the family may have.
- Emergency Department Allies, which encompassed five hospitals in Milwaukee, developed a Web-based system to track and monitor pediatric asthma-related emergency department visits and designed a strategy for providing education to families about care and self-management.
- Improving Pediatric Asthma Care in the District of Columbia focused on recruiting patients who use the emergency department into an educational program that taught them how to manage the disease. The program also coordinated with school nurses and local organizations to facilitate other services and to provide necessary equipment.

In January 2005, the American Academy of Allergy, Asthma & Immunology, the Robert Wood Johnson Foundation, and the CDC hosted a conference of experts to review the results of the Emergency Department Demonstration program and a similar program funded by the CDC. Two main issues were discussed: (1) Should emergency departments expand their asthma treatment role beyond immediate

treatment of asthma attacks? And (2) If so, what should their role be? The answer to the first question was a clear yes. As for the second—the role of emergency departments—the conference participants recommended assessing the level of a patient’s chronic asthma, providing limited patient and family education, and referring the patient to a health professional based in the community.¹¹

Developing a Blueprint for Policy Action

The RAND Corporation was funded to “develop policy options and recommendations for improving childhood asthma outcomes nationwide.” It worked with an expert panel to develop six policy goals and eleven policy recommendations, which include “improving asthma care in primary care settings; teaching children with asthma and their families how to better manage the illness; providing coordinated case management to children at high risk for asthma; and developing model health care packages for essential childhood asthma services.”¹²

The recommendations developed through this project were published in a series of three RAND reports. The final project report, *Improving Childhood Asthma Outcomes in the United States: A Blueprint for Policy Action*, was issued in 2001. The recommendations were published in an article in the June 2003 issue of the journal *Pediatrics*.¹³

Reducing Financial and Other Barriers

The Center for Health Care Strategies coordinated an eighteen-month project, *Exploring Barriers to the Financing and Treatment of Pediatric Asthma*, which investigated the limits on financing and treatment for pediatric asthma. The results of the study were to have been presented at a conference in September of 2001, but due to the events of 9/11, this was changed from an in-person meeting to a telephone conference call with leaders in the field. In October 2001, the Center published the results of its research as a chartbook, *Asthma Care for Children: Financing Issues*, designed to help states, health plans, and policymakers.¹⁴

Conclusion

The pediatric asthma initiative represents a short-lived experiment by the Foundation to concentrate on a single specific chronic condition. Conceptually, the Foundation’s approach—supporting research, policy, advocacy, community coalitions, and physician education—paralleled the wide-ranging approach that the Foundation adopted in its efforts to reduce smoking and reverse obesity. The Foundation’s interest in

pediatric asthma was met, according to an internal assessment, by overwhelming support from leaders in the field. The assessment noted, however, that implementation suffered since the key people associated with pediatric asthma within the Foundation left to take other jobs, leaving the oversight at the Foundation in something of an orphan status. Despite this, the programs were able to make progress, thanks largely to the active participation of those who were leaders in the field.

The pediatric asthma initiative appears to have had a positive influence on the field, as illustrated by other organizations replicating the community coalition approach. During the initiatives' first year, the National Heart, Lung, and Blood Institute funded eight coalitions very similar to the Allies Against Asthma coalitions; the CDC followed by launching its own program of community coalitions; and The California Endowment followed suit by supporting eight coalitions in California.

On a substantive level, the initiatives demonstrated how emergency departments can play a greater role than simply treating patients who show up in the midst of an asthma attack, how Medicaid managed care plans (and, presumably, other managed care plans) can better organize their services for asthmatic children, and how community coalitions can spur coordinated efforts at the local level to help patients and their families understand and manage asthma. One indication of the regard in which the Allies Against Asthma coalitions are held is their ability to raise funds to continue their activities after Robert Wood Johnson Foundation funding ends. The coalitions in Philadelphia, Milwaukee, Long Beach, and Puerto Rico have found support from other donors to sustain their work.

Interestingly, several of the Allies coalitions involved are exploring whether or not they should tackle other health issues in their communities, such as childhood obesity. Although there is debate about the value of community coalitions in addressing social problems,¹⁵ it seems that building an effective coalition is half the battle, and once people are organized and impassioned, they are likely to be in a position to take on other issues besides asthma. Insofar as the asthma initiatives were developed initially to see whether efforts to combat a single chronic illness would have spillover effects applicable to other chronic diseases, this may turn out to be their most significant long-term contribution.

Notes

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