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Allies Against Asthma: A Program to Combine Clinical and Public Health Approaches to Chronic Illness

An RWJF national program

SUMMARY

Allies Against Asthma: A Program to Combine Clinical and Public Health Approaches to Chronic Illness—a national program of the Robert Wood Johnson Foundation (RWJF)—supported the efforts of seven community-based coalitions to improve the management of pediatric asthma in their areas. The program—including research activities to evaluate the coalitions and their impact—ran from 1999 to 2008.

The coalitions implemented comprehensive asthma management strategies to improve the medical care, education and support of asthmatic children and their families in low-income neighborhoods and to stimulate environmental and other policy initiatives to increase the community's capacity to control the disease.

The seven coalitions were in (1) King County (Seattle), Wash.; (2) Long Beach, Calif.; (3) Milwaukee; (4) Norfolk and the surrounding Hampton Roads area of Virginia; (5) Philadelphia; (6) San Juan, Puerto Rico and (7) Washington, D.C. Coalition members included health care providers, government agencies (including health departments), schools and nonprofit organizations, as well as parents and caregivers.

Key Findings

National program office staff included the following findings from the evaluation of *Allies Against Asthma* in a report to RWJF:

- The seven coalitions made or contributed to a total of 90 changes in pediatric asthma-related policies and systems, ranging from improved practices within single health care institutions to revisions of citywide policies and state laws.
- Based on parent surveys, children in neighborhoods targeted by the coalitions for intervention experienced a greater reduction in recent asthma symptoms than did children in nontargeted comparison neighborhoods.

- Compared to parents in comparison neighborhoods, parents of children with asthma in the intervention neighborhoods showed significant improvement on two quality-of-life survey questions—how often they felt helpless or frightened when their child experienced breathlessness or other asthma symptoms and how often they felt angry that their child had asthma.

Program Management

The national program office for *Allies Against Asthma* was at the University of Michigan in Ann Arbor under the direction of Noreen M. Clark, Ph.D. In addition to overseeing and assisting the coalitions, Clark and her program staff were responsible for evaluating the impact of the coalitions and their interventions.

Funding

The RWJF Board of Trustees authorized the program in July 1998 for up to $12.5 million. Initially approved for four years and later extended, the funding supported the coalitions from 2001 to 2006 and the national program office—including its evaluation activities—from 1999 to 2008.

In 2005, the W.K. Kellogg Foundation awarded the University of Michigan a $199,954 grant to support the evaluation of the program's impact.

THE PROBLEM

The number of Americans with asthma grew dramatically in the 1990s, and the increase among children was especially troubling.

Between 1980 and 1995, the prevalence rate of asthma among the nation's 17-and-under population more than doubled—from an estimated 3.6 percent to 7.5 percent, according to the federal Centers for Disease Control and Prevention (CDC). Of the some 15 million Americans with asthma in the late 1990s, about a third were under 18.

Asthma is a chronic inflammatory disease of the airways characterized by recurrent episodes of breathlessness, wheezing, coughing, tightness of the chest and other breathing difficulties—conditions that take a heavy toll on the ability of young patients to lead active, normal lives.

Traditionally a leading cause of school absenteeism, asthma accounted for an estimated 14-million school absence days in 1996, up from 6.6 million in 1980.

An acute exacerbation of asthma[1], commonly called an asthma attack, can be life threatening. In an attack, there is a buildup of mucus, swelling of air tubes and tightening of muscles around air tubes, resulting in breathing difficulty. Pediatric asthma was—and continues to be—responsible for tens of thousands of hospitalizations and emergency room visits a year. Between 1979 and 1996, the number of children dying annually from asthma increased almost threefold—from 93 to 266, the CDC reported.

Asthma affects all populations but has a disproportionate impact on economically disadvantaged, urban and minority groups. Blacks experience asthma-related hospitalizations and death at almost triple the rate of Whites, according to the CDC.

Asthma Control

Although there is no known cure for asthma, advances in scientific understanding of the disease's underlying mechanisms have produced treatment tools and management strategies that can improve the health of asthma sufferers.

There are two types of medications physicians can prescribe:

- Short-acting medications, known as relievers and rescue medicines are used for quick relief once an attack starts. They act rapidly to open the breathing passages and relieve acute asthma symptoms. Relievers are not effective in controlling the underlying disease itself.
- Long-term control medications are prescribed to lessen the number and severity of attacks. They are used daily to prevent the symptoms of asthma and reduce the frequency and severity of attacks. Inhaled corticosteroids are generally considered the most effective anti-inflammatory medication available for long-term control. Once an attack has started, controllers are not effective in bringing relief.

Providers can also help young asthma patients and their parents by providing a written, individualized asthma action plan[2] that:

- Identifies early warning signs of an attack.
- Outlines recommended doses and frequencies of medication for quick relief and long-term control.
- Indicates when to seek help from a doctor.

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[1] **Acute exacerbation of asthma:** An asthma attack in which build up of mucus, swelling of air tubes and tightening of muscles around air tubes results in breathing difficulty. Asthma attacks may be mild, moderate or severe.

[2] **Asthma action plan:** A plan developed jointly by the health care provider and the asthma patient to help manage the disease. Plans identify early warnings signs of an attack, outline recommended doses and frequencies of medication for quick relief and long-term control and provide emergency contact information.

- Provides emergency contact information.

Another critical step is to identify and mitigate environmental conditions in the home that can cause the child's airways to become inflamed, swollen and clogged. These conditions, called triggers, include secondhand tobacco smoke, dust mites, cockroaches, mold, family pets and outdoor air pollution, such as industrial emissions and automobile exhaust.

Mitigation can be as simple as removing stuffed toys from a child's room, installing mattress and pillow covers and eliminating clutter that sustains roaches and other pests. (Non-environmental conditions, such as upper respiratory viral infections, also can be a factor in asthma attacks.)

Despite the knowledge and resources now available to control asthma, many parents of asthmatic children and even some health care professionals do not take full advantage of these tools. Education in asthma-management strategies is an important and widespread need, health authorities agree.

An Atlanta Initiative

In 1995, a coalition of organizations in Atlanta developed a community-based, multicomponent program aimed at reducing the incidence of pediatric asthma within an impoverished section of the city.

Called *Zap Asthma*, the initiative involved the medical and hospital community, managed care, school system, universities, and public health and environmental organizations, as well as individual community members.

Working together, these diverse interests developed an asthma-management strategy that emphasized allergen control and health education. Home environment audits and family-centered health instruction in smoking cessation and other topics were major components.

Although too new to generate evidence of effectiveness, the Atlanta effort drew attention across the country and sparked interest in replicating the coalition approach in other cities.

CONTEXT

Improving the quality of care of people suffering from chronic health conditions has been a key goal of RWJF since its founding as a national philanthropy in 1972.

In the late 1990s, a former RWJF program officer, Beth A. Stevens, Ph.D., was interested in determining whether a greater emphasis on holistic care—particularly efforts to increase involvement of the patient in his or her own care—could improve chronic illness outcomes.

The Atlanta initiative on asthma—especially its emphasis on stimulating family engagement in management of the disease—appeared to be just that kind of approach. Using *Atlanta Zap* as a model, Stevens proposed a grant program to demonstrate the ability of community-based coalitions to implement a comprehensive attack on pediatric asthma.

In July 1998, the RWJF Board of Trustees authorized spending up to $12.5 million to implement the initiative, named *Allies Against Asthma: A Program to Combine Clinical and Public Health Approaches to Chronic Illness (Allies Against Asthma).* Initially approved for four years and later extended, the program and its funding ran to June 2008.

An Enlarged Asthma Effort

Simultaneously, another group of RWJF program officers was conducting a separate examination of how RWJF might strengthen its efforts to improve chronic care. One idea was to focus closely on a few, specific chronic conditions.

In addition to benefiting people suffering from those particular illnesses, a set of in-depth, disease-specific initiatives might produce general models of care that could be applied to chronic conditions of all kinds, these staff members believed.

Influenced by asthma's increasing prevalence and its status as the most common chronic disease of childhood, the program officers, led by Seth Emont, Ph.D., (and including Doriane Miller, M.D., and Robin Mockenhaupt, Ph.D., M.P.H.) recommended that pediatric asthma be the focus of RWJF's first disease-specific effort. (Initiatives on diabetes and depression followed.)

In response, the RWJF board in July 1999 authorized $9.75 million (in addition to the $12.5 million previously approved for *Allies*) to support a spectrum of asthma-specific initiatives under the umbrella name *Managing Pediatric Asthma: Improving Clinical Care in Vulnerable Populations.* The major components were:

- *Improving Asthma Care for Children,* a $3.2-million national program to test new asthma-management approaches by Medicaid managed care organizations, which was administered by the Center for Health Care Strategies. See Program Results for more information.
- *Managing Pediatric Asthma: Emergency Department Demonstration Program,* a $3.5-million national program to improve hospital emergency department systems for treating pediatric asthma patients and educating their parents. The American Academy of Allergy, Asthma and Immunology managed this program. See Program Results for more information.
- A $2.4-million project to expand and evaluate Physician Asthma Care Education (PACE)—a curriculum designed to improve the ability of primary care physicians to

treat pediatric asthma patients and communicate effectively with their parents. A team at the University of Michigan School of Public Health—where PACE was originally developed—carried out this work. See Program Results on ID# 037658.

Although *Allies Against Asthma* had a separate origin and funding authorization, RWJF came to view it as part of this omnibus asthma-specific initiative. Accordingly, the Foundation formed a Pediatric Asthma Steering Committee composed of the leaders of *Allies Against Asthma* and the other asthma programs to coordinate activities and share lessons learned.

Also, at the conclusion of the asthma programs, RWJF disseminated their results in a single communications package. (See Afterward.)

PROGRAM DESIGN

After incorporating *Allies Against Asthma* into the Foundation's multipronged asthma initiative, but before issuing the call for proposals, RWJF staff made some design changes in the program from the original version authorized in 1998. (For an explanation of the changes, see Appendix 1.)

The final Allies design implemented in 1999 called for the program to support broad-based asthma coalitions in up to eight communities across the nation. Each coalition would develop and implement a comprehensive asthma-management plan.

The coalitions were to target children in low-income families dependent on publicly financed health care and safety-net providers. The program's September 1999 call for proposals set three primary objectives:

- Reduce hospital admissions, emergency room visits and missed school days.
- Enhance the quality of life of children with asthma.
- Develop a sustainable strategy for asthma management in the community.

If the demonstrations proved successful, their approaches could serve as models for other communities interested in improving the management of asthma and other chronic conditions, the RWJF staff believed.

Two Funding Stages

The call for proposals requested only one application per community. Either a public agency or a private tax-exempt organization could apply on behalf of the local collaboration. RWJF would fund the selected sites in two stages:

- A one-year grant of up to $150,000 to support the coalition's organization and planning activities.

- For coalitions that the national advisory committee judged had successfully completed the planning process, sites were eligible to apply for a three-year grant of up to $1.35 million to implement the interventions. RWJF required the coalitions to provide local cash and in-kind contributions totaling a third of the proposed coalition budget.

The RWJF money could go for staff salaries, consulting fees, data processing services, equipment and other expenditures essential to the local project—but not for patient care.

The coalitions were to include representatives from a wide range of private and government entities, such as the local school system, health care providers, health plans, economic development groups, and organizations focused on public health, housing and the environment. Community residents, including parents of children with asthma, were to participate as well.

THE PROGRAM

Management

RWJF established the national program office for *Allies Against Asthma* at the University of Michigan School of Public Health in Ann Arbor under the direction of Noreen M. Clark, Ph.D. In addition to overseeing the site-selection process and managing the program, Clark and her staff were responsible for providing technical assistance to the coalitions and evaluating their impact.

In naming Clark to run the program, RWJF said she combined expertise in clinical and preventive approaches with a talent for building community coalitions. Clark, whose primary research specialty is disease management, also directed the Physician Asthma Care Education (PACE) project for RWJF. For more information, see Program Results on ID# 037658.

At the program's start and for most of its duration, Clark was dean of the School of Public Health. In 2005, she gave up the deanship to start the Center for Managing Chronic Disease, an interdisciplinary research organization at the university. The Allies national program staff moved with Clark to her new academic home.

The initial deputy director of *Allies,* Linda Jo Doctor, M.P.H., left the staff in 2005. Her successor, Amy R. Friedman, M.P.H., had been the program's technical assistance director. Primarily as a cost-saving measure, Friedman continued to handle that function along with the deputy's duties of day-to-day program supervision.

The program staff included an evaluation director, Laurie Lachance, Ph.D., plus a research specialist, data analyst and other support personnel. Consultants assisted with

various technical needs, such as website and database development, and with the program's evaluation.

For a summary of the office's technical assistance services, see Appendix 2. For a description of its evaluation activities, see Evaluation.

National Program Office Funding

To support the national program office, RWJF awarded the University of Michigan:

- Seven grants totaling $4.3 million for program direction and technical assistance.
- Five grants totaling $688,822 for evaluation-related activities.
- Four supplemental grants totaling $255,437 for initiatives related to the *Allies Against Asthma* program.

In September 2005, the W.K. Kellogg Foundation awarded the University of Michigan a 40-month, $199,954 grant to support the *Allies* evaluation.

National Advisory Committee

RWJF established a 15-member national advisory committee to help select the program grantees, provide technical assistance to the coalitions and support the national program staff in managing the program and in the design of the program's evaluation.

The committee members included clinicians, researchers and public health officials as well as one parent of a child with asthma. The chair was Floyd Malveaux, M.D., Ph.D., then dean of the Howard University College of Medicine and subsequently executive director of the Merck Childhood Asthma Network. The full membership list is online.

The Planning Phase

The national program office received 254 letters of intent—the first step in the application process—and after a review, invited organizations in 26 communities to submit full proposals. The 26 included urban and rural communities across the country.

The national advisory committee selected 13 of the 26 for site visits and in November 2000, following the visits, recommended that RWJF award planning grants to coalition efforts in these eight communities:

- Albuquerque/Bernalillo County, N.M.
- King County (Seattle), Wash.
- Long Beach, Calif.
- Milwaukee, Wis.

- Norfolk and the surrounding Hampton Roads area of Virginia
- Philadelphia, Pa.
- San Juan, Puerto Rico
- Washington, D.C.

See Appendix 3 for the grantee names and other site-specific grant details.

The coalitions used the planning funds to assess the asthma problem in their communities and plan a locally tailored intervention strategy. They also used the planning period to secure matching funds for the implementation phase.

The Implementation Phase

In January 2002, based on the advisory committee's recommendation, RWJF awarded implementation grants to seven of the eight planning sites. The Albuquerque/Bernalillo County coalition—in the view of program leaders—was not ready to move into the implementation phase, and consequently that site received no further funding. (The coalition dissolved shortly thereafter.)

Initially, the seven implementation grants—each approximately $1.35 million—were to last three years, but RWJF extended all of them to give the coalitions additional time to complete their planned activities. The extensions varied from six to 20 months, with the grants ending between June 2005 and August 2006.

Coalition Characteristics: A Mixture

The seven coalitions entered the *Allies* program at different stages of development. Four formed in response to the program's call for proposals while three already existed in some form and had experience working on asthma or other health problems.

This mixture was intentional, according to the national program staff. By selecting coalitions of varying maturity, the program was more likely to demonstrate how coalitions function and succeed, Clark and her colleagues wrote in a 2006 journal article in *Health Promotion Practice.*

As a result of their different experience levels, the coalitions took different amounts of time to fully organize and begin implementing their plans—30 months in one case (San Juan). The coalitions also varied in other respects; the following provides an overview:

- **Size:** The coalitions varied from 40 to 76 members. Overall, 76 percent of the coalitions' members represented an organization and 11 percent participated as individuals. (The remainder represented themselves and an organization.)

Organizational coalition members included health care providers, local and state health departments, various city departments (e.g., air quality and legal aid), schools and community groups. Individual participants were parents and caregivers.

- **Staff:** While staffing levels fluctuated, in the first four years each site employed an average of six full-time individuals (or equivalent) to manage the coalition, conduct activities and coordinate evaluation research.
- **Organizational structure:** Although the precise leadership arrangement varied, each coalition had formed workgroups or committees to carry out prescribed tasks. They also formed a steering or executive committee composed of leaders from the committees or workgroups. Some steering committees also included at-large members from community organizations.
- **Grantee role:** The grantee organizations played different leadership roles but most provided physical space for coalition activities and hired at least some of the coalition staff. The grantees were:
  - Three children's hospitals (Long Beach, Calif., Milwaukee and Norfolk, Va.).
  - A nonprofit research organization (San Juan, Puerto Rico).
  - A nonprofit health promotion organization (Philadelphia).
  - A county health department (King County [Seattle], Wash.).
  - A community foundation (Washington).

For background information about each site, see Appendix 4.

The Intervention Plans: Unique, but with Similarities

As did the coalitions, their communities differed in demographics and other characteristics. Thus, not surprisingly, the plans developed by the seven groups differed in the specific types and mix of interventions. There were, however, general similarities:

- All of the sites employed education and training in some form—directed at families in which children had asthma, physicians, nurses, school personnel or others—to break down the structural barriers to quality asthma care. Examples:
  - Sending nurses or community health workers (CHWs) into the homes of children with asthma to instruct the parents in management techniques was a common intervention.
  - Another was offering the PACE curriculum to help physicians treat, track and educate their pediatric asthma patients and parents. See Program Results for more information on the curriculum.

- All seven sites implemented interventions aimed at improving the indoor environment. Examples:
  - Identification and removal of in-home allergens were prominent tactics.
  - Providing trigger-resistant mattress covers and nontoxic cleaning supplies was also common.
- All of the sites tried to bring about lasting change in health-related policies and systems—ranging from operational reforms affecting single institutions to new communitywide practices. A central tenet of *Allies Against Asthma* was that changing health policies and the delivery system was the most effective way to influence pediatric health—more effective than instituting programs and services. Examples:
  - Developing a standardized asthma action plan for use by local health plans, hospitals, Medicaid providers and schools—a systems change designed to reduce confusion over and encourage use of action plans. Asthma action plans are developed by the health care provider to help parents manage their child's asthma. Plans identify early warning signs of an attack, outline recommended doses and frequencies of medication for quick relief and long-term control, and provide emergency contact information.
  - Advocating tougher local outdoor air quality standards—a policy change to improve the environment for asthma sufferers. (The coalitions used non-RWJF funds to support any lobbying activities they undertook, according to Clark, the program director.)

For a brief overview of each site's general strategy, see Appendix 5.

EVALUATION

The *Allies* national program office was responsible for evaluating the program as well as managing it. RWJF's research and evaluation (R&E) department, under the direction of Jim Knickman, Ph.D., was designing more evaluations to be conducted by programs themselves at the time *Allies Against Asthma* was being developed. With the original program officer Seth Emont, Ph.D., a member of R&E, self-evaluation was included in *Allies'* design. Each component of the program included a self-evaluation so that all components of the program could contribute to documenting the program's overall impact. In addition, Clark, the program director, considered evaluation research an important aspect of the *Allies* initiative and sought inclusion of that function in the national program office.

She and her university colleagues were interested not just in delivering a program, but in determining what could be learned about the collaborative process, Clark said in an interview conducted for this report.

While community coalitions were common across the country, there was little evidence up to that point that they were effective in reducing health risk, Clark said. There also had been little research into how coalitions achieved what positive results they did have.

(One likely reason for the scarcity of research—Clark and her team pointed out in a 2006 journal article in *Health Promotion Practice*—is that evaluation of community-based work faces a number of methodological challenges, including the logistical difficulty of obtaining a control group or other comparison mechanism).

Asked if she had any concern that the national program office's dual role as both program manager and evaluator presented a potential conflict or could open the findings to skepticism, Clark said she did not.

To the contrary, the staff's involvement in—and understanding of—the program permitted a greater capacity for evaluation than a third-party consultant would be likely to achieve, Clark said. Also, the evaluation team did not include any of the staff providing technical assistance to the coalitions.

Multiple Evaluation Approaches

The national program staff, consultants and advisory committee members collaborated with the local coalition leaders to design a cross-site evaluation of the coalitions' processes and outcomes.

The consensus plan that emerged provided for a variety of qualitative and quantitative research methods to examine the impact of the seven coalitions and the factors that influenced the way the coalitions functioned. The following were among the principal components of the evaluation:

- The national program office subcontracted with a unit of Battelle to interview individuals in the project communities about the coalitions' planning processes and operations. Interviews took place in the middle of the program (summer 2003 and fall/winter 2004).
- The individual coalitions surveyed parents and other caregivers about halfway through the program (in May 2003) to measure the program's intermediate impact on families with asthmatic children.
- The individual coalitions conducted a baseline survey (from May to October 2003) and a survey one year later of members to assess coalition processes and structure, including coalition functioning, leadership and effectiveness.
- The individual coalitions entered information about coalition activities and results into a Web-based database.

- To gauge the program's impact on asthma-related health outcomes, the program staff initiated the collection and analysis of Medicaid data from the federal Centers for Medicare & Medicaid Services (CMS) on children's use of hospital and other health care services in the coalition communities and a set of noncoalition comparison communities. However, program staff could not complete this assessment during the program because the final data from CMS will not be available until 2011.

  The W.K. Kellogg Foundation grant supplemented the RWJF funding for this portion of the evaluation.

- At the end of the program, the evaluation team identified the number and types of policy and system changes that the coalitions made either alone or in partnership with other organizations.

For details of these components of the evaluation, see Appendix 6.

CHALLENGES

In the interview for this report, Clark identified the following as the two major challenges that confronted the national program office staff:

- **Shifting focus from initiating programs and services to changing policies and systems was a difficult transition for some coalitions to make.**

  Programs and services are concrete and have constituencies while policies and systems are abstractions. Some coalition members experienced in providing programs and services had difficulty accepting the idea that changing health policies and the delivery system held greater potential to influence the health of children on a large scale.

  In meetings and phone calls, the national program staff and advisory committee members emphasized the lasting value of systems and policy change. Also in program meetings, the leaders of coalitions that embraced the concept explained their interventions—a helpful teaching tool for other coalitions. It took time, but eventually all of the coalitions did make the transition—including one that had to shelve its initial approach and start over.

- **Helping the coalitions find and maintain a balance between collaboration and action was difficult in some of the communities.**

  A group made up of people with diverse interests and backgrounds is likely to produce a more effective solution to a community problem than is a homogeneous group. However, there is a tension between creating a collaborative environment and maintaining the level of participation and energy among the collaborators that is necessary to implement the strategy.

  In short, it is one thing for a collaborative group to identify solutions and another to bring them about. The program staff addressed the challenge by making a concerted

effort to encourage the coalitions to ensure that all members participated in the decision-making and felt they had a voice in determining the action to be taken.

In a July 2008 written report to RWJF, the national program office identified these additional challenges:

- **Completing their planned tasks in the time initially allotted was difficult for the coalitions, particularly those that had little or no experience at the program's start.**

  A three-year period—the time initially set for the implementation grants—may be too short to achieve the kind of sustainable, communitywide changes the program intended. All seven sites needed more than three years and consequently received no-cost grant extensions.

- **The time lag in obtaining health care utilization data coupled with the delayed completion of the coalitions' work presented a significant barrier to evaluation.**

  When the initial plan to work with local hospital utilization data proved infeasible, the program office partnered with CMS to obtain Medicaid utilization data for the coalition and comparison communities.

  CMS's agreement to support the research effort was fortunate. However, the time it took to get the Medicaid data—a minimum of three years after the Medicaid-funded services were provided—was longer than anticipated. This time lag in conjunction with extension of the RWJF grant periods made an outcome assessment of the coalitions difficult—and impossible to complete within the program period.

OVERALL PROGRAM RESULTS

Evaluation Findings

The national program office of the *Allies Against Asthma* program reported the following findings from their evaluation in a report to RWJF in July 2008:

- **The seven coalitions made or helped make a total of 90 changes in pediatric asthma-related policies and systems, ranging from improved practices within single health care institutions to revisions of citywide policies and state laws.**

  The national program office divided the changes into five general categories:

  — Improved clinical practices—25 changes.

    Example: Creation and funding of an asthma coordinator position in the local children's hospital (Milwaukee).

  — Improved coordination and standardization—25 changes.

Example: Establishment of a telephone-based, communitywide system to assess, refer and support families with children with asthma (Philadelphia).

— Improved environmental conditions—18 changes.

Example: Passage of legislation—supported by grassroots advocacy of coalition participants—that prohibited idling of diesel trucks in residential neighborhoods (Long Beach, Calif.).

(A number of coalitions cited legislative changes—including ordinances banning indoor smoking—among their accomplishments. Clark, the *Allies Against Asthma* director, says no RWJF grant money went for lobbying; the coalitions used other funding to support any lobbying activities they undertook.)

— Institutionalized efforts to improve asthma management by family members—four changes.

Example: The offering of management education by community clinics and medical practices (Hampton Roads, Va.).

— Other types of improvements—18 changes.

Example: Establishment of a policy allowing children with a valid asthma action plan to carry and self-administer asthma medication in school settings (Washington).

- **Children in areas targeted by the coalitions for intervention experienced a greater reduction in recent asthma symptoms than did children in nontargeted comparison groups, based on self-reports of parents.**

According to the national program staff's analysis of aggregate *Core Caregiver Survey* data for five sites:

— Children in the target communities had, on average, 1.45 fewer days with asthma symptoms during the two weeks before the follow-up survey compared to the two weeks before the baseline survey one year earlier. By contrast, the non-intervention comparison children experienced a reduction of 0.57 days.

The target group also registered a significantly greater reduction in nighttime symptoms over the previous two weeks than did the comparison group. The intervention children experienced, on average, 1.55 fewer nights with symptoms while the comparison group had a reduction of 0.49 nights.

— Over a one-year period, the intervention group had a significantly greater reduction in nighttime symptoms (a decrease of 23.88 nights compared to an increase of 2.4 nights for the comparison group). However, in daytime symptoms over the past year, the intervention group's reduction was not statistically significant compared to the reduction for the comparison group.

Staff said the health of asthmatic children generally tends to improve with age, possibly explaining why the comparison group registered some reduction in symptoms.

- **Parents of children with asthma in the intervention neighborhoods showed significant improvement on two quality-of-life questions compared to parents in nontargeted comparison groups.**

  — In the follow-up survey, intervention parents improved their score when asked (1) how often they felt helpless or frightened when their child experienced breathlessness or other asthma symptoms and (2) how often they felt angry that their child had asthma. The improvement was significantly greater than that of comparison parents.

  The national program staff said these results suggest the intervention parents had a greater sense of emotional control compared to the comparison parents. Emotional control is relevant to the caregiver's quality of life, the staff indicated.

  — On a third quality-of-life question—how worried parents were about their child's asthma medications and side effects—the intervention parents' scores increased significantly less than those of the non-intervention parents. A likely explanation, according to the staff, is that the intervention parents became more aware of the need to monitor asthma medications.

While there was a significant difference between the two groups on these three individual quality-of-life survey items, there was no significant difference when all of the survey's quality-of-life items were analyzed in aggregate, according to staff.

The program office characterized the survey results as intermediate outcome findings and did not present them as conclusive. However, a July 2008 press release issued by the national program office quoted Clark as saying about the *Allies* results to date:

> Initial results are promising and demonstrate that coalitions are able to bring about changes in policies and practices in their communities that have a direct and positive impact on families living with asthma.

In an interview, Clark indicated the statement referred principally to the survey data on symptoms reductions and the number of policy and system changes made by the coalitions.

Battelle Qualitative Evaluation Report

In an April 2005 document (*Qualitative Evaluation of Allies Against Asthma*) prepared for the national program office, Battelle investigators concluded:

- **"In many respects, the *Allies* coalitions as a group are exemplary, not only as a credible approach to addressing the multi-faceted problem of pediatric asthma,**

but also as models of how collaborative health promotion efforts can work to effect community change."

See Appendix 7 for other findings from the Battelle report.

Key Site Activities and Results

The national program office suggested that the key site activities and results could be grouped in five general categories or themes.

1. **The *Allies* coalitions helped children and families.** Examples:

   — In Milwaukee, an in-home education program helped low-income families with pediatric asthma learn more about the disease-including how to combat dust mites, cockroaches and other allergens.

   — In Philadelphia, trained asthma care coordinators staffed a telephone "hot line" that parents could call for immediate answers to pediatric asthma questions and problems and for referrals to appropriate health care and social services.

   When three-year-old Jimmy Townsend was diagnosed with asthma, his mother, Octavia, faced a bewildering array of medicines and delivery devices. "In the beginning, I was not comfortable" handling the medication, says Townsend, a resident of Milwaukee's north side. Read more about how the Milwaukee Allies coalition helped Jimmy and his mother-and about coalition efforts in Philadelphia and Long Beach to improve the lives of children with asthma and their families.

   — In San Juan, the local managed care company instituted improved coverage of pediatric asthma medication and equipment used by families living in the city's largest housing project.

2. **The *Allies* coalitions changed physician practices.** Examples:

   — In the Hampton Roads area of Virginia, doctors changed the way they wrote prescriptions for spacers so families could get Medicaid coverage for two of the devices-one for home and one for school. Previously, many young asthma sufferers had just one spacer-and holding onto it from home to school and back again often proved difficult. A spacer is a device, also known as a holding chamber, that attaches to an inhaler and captures the right amount of medication, making it easier to administer an effective dose. Spacers are often used to help children, older adults and others who have trouble holding their breath, as required for effective inhaler treatment.

   The typical 15-minute appointment does not give physicians much time to learn about the everyday challenges facing pediatric asthma patients and their parents, says Cynthia S. Kelly, M.D., co-director of the Hampton Roads coalition. Read more about how her coalition addressed that problem-and also about efforts in Seattle and Long Beach to change physician practices.

— In Long Beach, 179 health care providers participated in a continuing medical education program on pediatric asthma care. In addition to increasing therapy skills, the sessions coached pediatricians in how to communicate effectively with parents about asthma and its control.

— In King County (Seattle) Wash., four clinics serving low-income areas instituted new procedures to better manage their pediatric asthma patients and link them to community resources.

3. **The coalitions empowered community members.** Examples:

— In Long Beach, a corps of parents from low-income, inner-city neighborhoods turned their personal struggles with pediatric asthma into a crusade for cleaner air and better housing. Their grassroots advocacy helped bring about restrictions on diesel trucks and alter plans for an interstate highway expansion project in the inner city.

The ability to attack a problem at different points and from different directions is the strength of the coalition approach—a strength demonstrated by the Allies program, says Friedman, deputy national program director. Read more about the benefits demonstrated by the program, as viewed by leaders of the coalitions in Philadelphia, Long Beach, Seattle and Milwaukee.

— In Milwaukee, an outreach worker went door-to-door in one of the city's poorest areas, motivating parents of asthmatic children to improve asthma control in their neighborhood as well as in their homes. Progress was slow, but the effort led to initial steps toward improvement of the area's rental housing units.

4. **The coalitions helped change policy.**

— In Philadelphia, the coalition partners developed a standardized asthma action plan for use by physicians throughout the city. Plans identify early warning signs of an attack, outline recommended doses and frequencies of medication for quick relief and long-term control and provide emergency contact information. Philadelphia's three main managed care organizations disseminated the form to some 600 providers in their networks.

"I don't understand much about politics—believe me, not a whole lot," Evangelina Ramirez, speaking in her native Spanish, told a Long Beach forum on air pollution in 2005. "But what I do understand is I have a child with asthma." Read more about how she and other Long Beach parents became environmental activists-and about the effort to empower parents in Milwaukee.

— In Hampton Roads, a similar effort produced a standardized asthma action plan endorsed by all seven school districts in the area and recommended for statewide use by the Virginia Asthma Coalition.

— In Washington, the coalition coordinated development of a policy permitting school children with a valid asthma medication plan to possess and self-

administer life-saving asthma medicines in school settings. The city council subsequently adopted the policy as a law.

5. **The coalitions demonstrated the benefits of a coalition approach to public health problems.**

   — In Long Beach, participants in the Allies coalition spanned a range of city agencies and community groups, allowing the program to go beyond the "the clinic walls" and raise awareness of the asthma problem communitywide, says Elisa Nicholas, M.D., M.S.P.H., founder of the Long Beach coalition.

   — In Milwaukee, the coalition included a service organization based in a poor, Black neighborhood-a factor essential to engaging the area's hard-to-reach families in the problem of pediatric asthma, says John Meurer, M.D., director of the Milwaukee coalition.

   — In Philadelphia, the coalition consisted of 102 individuals from more than 40 organizations representing health care, education, insurance, government and parents. The paid staff was small but because of its breadth of participation, the coalition was able to have an impact in a wide range of areas, says Vanessa Briggs, M.B.A., executive director of the coalition's oversight organization.

One barrier to improved pediatric asthma control in Philadelphia's high-risk neighborhoods was the absence of a standardized asthma action plan. Without standardization, families encountered different kinds of action plans as they moved from one health care organization to another, causing confusion and discouraging use of any plan. Read more about how the Philadelphia coalition addressed the problem-and about efforts in Norfolk and Long Beach to affect policy.

Communications

Clark, the program director, says the development and dissemination of the *Allies* community coalition model was the program's biggest contribution-one that she believes will benefit community collaborative work outside the program's seven sites and beyond pediatric asthma.

A key vehicle for disseminating the model—and information about all aspects of the *Allies* program—was the April 2006 supplement to the journal *Health Promotion Practice*. The supplement contains 15 articles by national staff members and site leaders. The articles examined the structure and activities of the coalitions, the role of the national program office and the components of the evaluation.

See the Bibliography for the individual article titles. RWJF funded the supplement through a $45,235 grant (ID# 052817) to the University of Michigan.

Another key dissemination vehicle was the website that the national program office developed to provide information about the program. The website includes an overview of each coalition's activities, a description of the evaluation and copies of various survey instruments and other products of the national program office and individual coalitions.

The products include a set of tools to assess asthma educational materials compiled in a report. The assessment tools were a response to the poor quality of many asthma publications-especially those in Spanish-that the coalitions found available to the public. The national program staff helped local coalition leaders develop the tools and posted the finished product on the website for other groups to use.

RWJF supported work on the assessment tools with a supplemental $41,137 grant (ID# 042225). The grant also funded communications training for national program staff and coalition representatives.

Additional Online Resources

In addition, the national program staff developed a public, online database of tools and materials of potential use to asthma coalitions and programs in general, not just the seven *Allies* groups.

Called the Allies Against Asthma Resource Bank, it identified more than 500 asthma-related educational materials, clinical protocols, evaluation instruments and other resources. At the conclusion of the *Allies* program, the national program staff made arrangements for the Indoor Environments Division of the U.S. Environmental Protection Agency (EPA) to maintain the database on the EPA-supported *Communities in Action for Asthma-Friendly Environments Online Network.*

The national program staff and coalition leaders made presentations at numerous professional meetings and conferences. They also worked with representatives of government agencies and private organizations to help develop and support other asthma coalitions and programs at the federal, state and local levels.

See the Bibliography for details of many of these communications activities, including a sampling of the conference presentations.

Two Additional RWJF Grants

RWJF awarded the University of Michigan two supplemental grants to support these Allies-related communications efforts:

- A one-day meeting in 2003-held in collaboration with the Centers for Disease Control and Prevention, National Heart, Lung and Blood Institute and the California Endowment-at which representatives of 33 asthma community coalition projects from around the country shared experiences and lessons (ID# 048762 for $69,543).

The grant also supported presentations by Allies staff and site personnel at five national health conferences, including the 2003 and 2004 annual meetings of the American Public Health Association.

- A three-day meeting in 2006 at which Allies national program staff and coalition leaders explored the potential for applying the community coalition approach to childhood obesity. The staff documented highlights of the discussions in a 2007 report (ID# 053736 for $99,522).

LESSONS LEARNED

The following were among lessons that members of the *Allies Against Asthma* national program staff learned from the *Allies* experience:

1. **Realize that it takes significant time, energy and patience to develop the processes necessary to bring diverse interests and individuals together to solve community problems.** Organization of the coalitions and implementation of their interventions took longer than expected, and required oversight and assistance by the program staff. "It takes patience, and it takes faith that if you spend the time and have the patience, you will get a better solution," said Clark.

2. **Be prepared to provide extensive technical assistance to new community coalitions-assistance in both the processes of collaboration and the technical details of health care policy.** Staff also spent a great deal of time providing technical assistance so that the sites had access to the knowledge and experience necessary to effectively implement their plans. (Program Director/Clark)

3. **Do not try to pressure members of a community coalition to make decisions or undertake tasks.** The *Allies Against Asthma* national program staff found that if coalition members are not yet ready to commit to a course of action, it is unproductive to try to force their hands. (Program Director/Clark)

4. **When relying on Medicaid health care utilization data for research, be prepared to wait.** Obtaining and organizing the Medicaid datasets proved to be a long, laborious process. This meant that program staff could not complete the evaluation during the program. However, this is the best dataset available in today's fractured health care system to meet the program's evaluation needs. (Program Director/Clark)

5. **Allow new community coalitions a minimum of two years for planning.** Nearly every *Allies* site had difficulty meeting the program's one-year planning schedule. The new coalitions needed time to develop relationships, an infrastructure and community reputation. The established coalitions needed time to engage new stakeholders, hire staff and complete other tasks. (July 2008 National Program Office Report to RWJF)

6. **Carefully select national advisory committee members based on their ability to bring to the initiative both needed expertise and personal commitment.** *Allies*

benefited significantly from an advisory committee that was deeply engaged in all facets of the program. (July 2008 National Program Office Report to RWJF)

7. **Nurture local site leaders and help them become champions for improved asthma management.** The *Allies* director leveraged her position to create opportunities for promising local leaders to become known in the field—a development that fostered sustainability of the coalitions and their work. (July 2008 National Program Office Report to RWJF)

8. **Foster cross-site relationships by creating opportunities that encourage information sharing and collaboration.** The *Allies* staff worked to promote congeniality and avoid competition among the coalitions. (July 2008 National Program Office Report to RWJF)

9. **Dedicate a full-time position on the program staff to overseeing the technical assistance effort.** The *Allies* technical assistance director was the link connecting the site leaders to the program office. (July 2008 National Program Office Report to RWJF)

10. **Don't skimp on site visits.** Site visits allowed the *Allies* staff and advisory committee members to get a more realistic understanding of the sites' processes, relationships, challenges and strengths. (July 2008 National Program Office Report to RWJF)

11. **Invest in dissemination technology, especially a website.** While up-front development costs were considerable, a well-organized, attractive website was critical to *Allies* for communication in the digital age. (July 2008 National Program Office Report to RWJF)

12. **Provide technical assistance in sustainability, starting at the very beginning of the initiative.** The program staff encouraged sites to consider sustainability issues at every stage of their development. (July 2008 National Program Office Report to RWJF)

AFTERWARD

The Sites

Six of the seven funded coalitions remained ongoing in some form after the close of *Allies Against Asthma*.

The exception was the Washington (D.C.), coalition, which dissolved at the end of 2007, two years after its RWJF funding ended. Lisa A. Gilmore, M.B.A., the group's former executive director, said in an interview that the coalition leadership felt other organizations provided better vehicles for moving the coalition agenda forward. A number of the *Allies* initiatives continued under other groups-public and private-and the coalition participants remained active in asthma work, she said.

The six continuing coalitions secured funding to sustain some but not all of their *Allies* interventions:

- King County (Wash.) folded a number of its *Allies* initiatives-including community health worker home visits-into a separate, federally funded health program (*Steps to Health-King County*) aimed at reducing the impact of chronic conditions and eliminating health disparities.
- The Long Beach, Calif., coalition expanded its focus to adjacent communities, supported by money paid by British Petroleum to settle a regional air pollution case.
- The Milwaukee coalition received support from the Children's Hospital and Health System to sustain coalition infrastructure and initiatives; the Medical College of Wisconsin provided funding for asthma education and care focused on three high-risk zip codes.
- The Norfolk and Hampton Roads coalition in Virginia, with some temporary state funding, shifted much of its asthma focus to policy change activities, particularly reducing secondhand-smoke exposure, according to the national program staff.
- The Philadelphia coalition obtained funding from the Merck Childhood Asthma Network and maintained some interventions, including the toll-free telephone-based referral and support service for asthma families. The Philadelphia partners also secured federal grant funds through the CDC for a chronic disease prevention program named *Steps to a Healthier Philadelphia.*
- The San Juan, Puerto Rico, collaborators also secured Merck funding to continue many of the Allies interventions and to expand them to other parts of the target area. (The group changed its name to La Red de Asma Infantil de Puerto Rico/Puerto Rico Childhood Asthma Network).

National Program Office

Clark and her staff at the Center for Managing Chronic Disease continued to collect Medicaid utilization data for the target and comparison communities and planned to complete the outcomes evaluation after they receive the final data. The Kellogg grant, which helped fund this work, ended at the end of 2008, and as of February 2009, Clark was seeking additional support.

In addition, the staff was working with coalition representatives to prepare an article reporting the caregiver survey results.

Robert Wood Johnson Foundation

RWJF hired a Philadelphia firm, Steege/Thomson Communications, to disseminate the key results and lessons of the Foundation's three asthma-specific national programs

(Allies Against Asthma, Improving Asthma Care for Children and *Managing Pediatric Asthma: Emergency Department Demonstration Program.)* The project had two phases:

- In 2005—under a $69,700 contract (ID# 046062)—Steege/Thomson developed a communications plan to bring the programs' most promising findings and replicable models to the attention of the health care and policy-making communities.
- In 2006 the firm received a $400,000 contract (ID# 052807) to implement the plan. The key results were:

  — A website describing the three asthma programs and profiling the work of each of their project sites, including the seven *Allies* coalitions. (Note: The site remained accessible after the firm's contract ended in January 2008, but the content was not kept current).

  Steege-Thomson conducted direct mail and e-mail campaigns to promote the site, which was launched in June 2007. At the conclusion of its contract, the firm reported that the site had received nearly 9,000 visits and 23,000 page views.

  — A media outreach effort to secure coverage of the RWJF programs and pediatric asthma issue, particularly in publications for health care professionals.

  — A free online continuing medical education program on asthma care designed for emergency clinicians. The Respiratory and Allergic Disease Foundation created the hour-long, for-credit program, entitled *Childhood Asthma: Building the Bridge between the Emergency Department and Long-term Care Settings.*

RWJF viewed the communication project as the culmination of its effort to build the asthma field. In recent years, RWJF has increased its focus on improving the quality of chronic care *generally* and no longer has a focus on any single disease.

Prepared by: Michael H. Brown
Reviewed by: Lori De Milto and Molly McKaughan
Program officers: Beth Stevens, Seth Emont, Elaine Cassidy and Jeane Ann Grisso

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APPENDIX 1

Program Design Changes

Beth Stevens, Ph.D., the RWJF program officer who originated *Allies Against Asthma*, designed the program to fund four demonstration sites to be selected from an invited list of 10 to 12 cities known to be interested in a coalition approach to improving asthma control.

The $12.5-million authorization anticipated that each site would need approximately $1 million a year, including RWJF grant funds and local cash and in-kind contributions.

Stevens left the RWJF staff to join Mathematica Policy Research immediately after the Board of Trustees' 1998 approval of *Allies*. Responsibility for the program's implementation then passed to the program officer designing the package of pediatric asthma initiatives.

This program officer, Seth Emont, Ph.D., believed that $1 million per site per year was too much money. He reasoned that a budget of that size would make sustainability of the coalitions and replication of their models difficult.

Consequently, Emont redesigned the program to fund up to eight coalitions, each to receive as much as $450,000 annually from RWJF supplemented by local resources. The program's total price tag remained $12.5 million.

In addition, Emont changed the site selection from an invitation-only process to a competitive call for proposals—a change designed to produce a wider range of asthma-control strategies.

Noreen M. Clark, Ph.D., the program director of *Allies*, supported the changes, and Emont presented the redesign to the RWJF Board of Trustees in April 1999 in conjunction with the award of the first *Allies* national program office grant to the University of Michigan School of Public Health.

APPENDIX 2

Technical Assistance

Providing technical assistance to the *Allies Against Asthma* coalitions was a key function of the national program office. Through staff and consultants, the office made an effort to help coalition participants master both the processes of collaboration and the technical aspects of health care policy.

Among the key ingredients of that effort were the following. The program staff:

- Held periodic meetings and conference calls with leaders of the seven coalitions and national advisory committee members to share ideas, experiences and resources.
- Conducted annual meetings for representatives of the grantees and their key partners. The sessions included guest presenters on the science of asthma and workshops on issues related to coalitions and collaboration.
- Made annual site visits to each coalition to assess progress and address potential problems. National advisory committee members and RWJF staff also participated.
- Sent weekly e-mails to the coalitions highlighting asthma research findings, potential funding opportunities to sustain the coalitions' work and other relevant information.
- Coordinated an effort by the coalitions to collect and evaluate asthma education materials available across the country, including materials written in Spanish.
- Hired consultants to visit coalition communities to offer specialized help with technical issues.

APPENDIX 3

Grant Details for the Eight *Allies Against Asthma* Projects

Albuquerque, N.M.

American Lung Association of Arizona/New Mexico

Coalition Name: Albuquerque/Bernalillo County Asthma Coalition

Planning Grant: ID# 041275 (January 2001–December 2001): $135,613

Project Director: Romelia Rodriquez, B.S.

(505) 265-0732

King County (Seattle), Wash.

Seattle-King County Department of Public Health

Coalition Name: King County Asthma Forum
Planning Grant: ID# 041271 (January 2001–December 2001): $149,809
Implementation Grant ID# 044215 (January 2002–December 2004): $1,348,282

Project Director: James Krieger, M.D., M.P.H.
(206) 263-8227

Long Beach, Calif.

Long Beach Memorial Medical Center
Coalition Name: Long Beach Alliance for Children with Asthma
Planning Grant: ID# 041281 (January 2001–December 2001): $128,101
Implementation Grant: ID# 044218 (January 2002–December 2004): $1,350,000

Project Director: Elisa Nicholas, M.D., M.S.P.H.
(562) 933-0430

Milwaukee, Wis.

Children's Health Systems
Coalition Name: Fight Asthma Milwaukee Allies
Planning Grant: ID# 041279 (January 2001–December 2001): $149,500
Implementation Grant: ID# 044214 (January 2002–December 2004): $1,350,000

Project Director: John R. Meurer, M.D., M.M. (414) 456-4116

Norfolk and Hampton Roads Area of Virginia

Children's Hospital of the King's Daughters
Coalition Name: Consortium for Infant and Child Health
Planning Grant: ID# 041280 (January 2001–December 2001): $148,862
Implementation Grant: ID# 044216 (January 2002–December 2004): $1,350,000

Project Co-Directors: Frances D. Butterfoss, Ph.D.
(757) 668-6429
Cynthia S. Kelly, M.D.
(757) 668-6443

Philadelphia, Pa.

Health Promotion Council of Southeastern Pennsylvania
Coalition Name: Philadelphia *Allies Against Asthma*
Planning Grant: ID# 041270 (January 2001–December 2001): $150,000
Implementation Grant: ID# 044217 (January 2002–December 2004: $1,350,000

Contact: Vanessa Briggs, M.B.A.

(215) 731-6150

San Juan, Puerto Rico

RAND Corp. (Santa Monica, Calif.)

Coalition Name: Alianza Contra el Asma Pediátrica en Puerto Rico (Allies Against Pediatric Asthma in Puerto Rico)

Planning Grant: ID# 041273 (January 2001–December 2001): $150,122

Implementation Grant: ID# 044219 (January 2002–December 2004): $1,349,526

Project Director: Marielena Lara, M.D., M.P.H.

(310) 393-0411 Ext. 7657

Washington, D.C.

Community Foundation of the National Capital Region

Coalition Name: National Capital Asthma Coalition (formerly D.C. Asthma Coalition)

Planning Grant: ID# 041269 (January 2001–December 2001): $150,000

Implementation Grant: ID# 044220 (January 2002–December 2004): $1,349,308

Project Director: Lisa A. Gilmore, M.B.A., M.S.W.

(301) 891-1663

APPENDIX 4

Background Information on the Seven Implementation Sites in *Allies Against Asthma*

King County (Seattle): King County Asthma Forum

The American Lung Association of Washington and the local health department convened the King County Asthma Forum in 1998 as a mechanism for sharing information about asthma in the community. The group had no funding or programming before joining *Allies Against Asthma*.

Long Beach, Calif.: Long Beach Alliance for Children with Asthma

In response to the *Allies* solicitation, a core group of local individuals who had collaborated on previous health-related efforts formed the Long Beach Alliance for Children with Asthma and applied for RWJF funding. A physician, a public health intern and personnel at a children's hospital and the local health department created the initial framework for the coalition.

Milwaukee, Wis.: Fight Asthma Milwaukee Allies (FAM Allies)

In 1994, a group of volunteers who had been involved in a local asthma surveillance project started a comprehensive asthma-control effort called Fight Asthma Milwaukee, known as FAM. The organization sought *Allies* funding to expand its efforts and, after becoming a program participant, amended its name.

Norfolk and the Hampton Roads Area of Virginia: Consortium for Infant and Child Health

The consortium formed in 1993 in response to concerns about childhood immunization rates in Hampton Roads—the coastal area of southeastern Virginia that includes Norfolk and six other cities (and a population of more than 1.5 million). Five years later, the group expanded its focus to include asthma, and when RWJF announced the *Allies* program, it saw an opportunity to further enhance that aspect of its work. Personnel at Eastern Virginia Medical School and Children's Hospital of the King's Daughters in Norfolk led the coalition.

Philadelphia, Pa.: Philadelphia *Allies Against Asthma*

Members of two existing Philadelphia asthma coalitions joined with other partners to apply for *Allies* funding as a single coalition. (The *Allies* rules allowed only one application per community.) Two nonprofit health organizations—Philadelphia Health Management Corp. and Health Management Council—took the lead in forming the new group, named Philadelphia *Allies Against Asthma*.

San Juan, Puerto Rico: Alianza Contra el Asma Pediatrica en Puerto Rico (Allies Against Pediatric Asthma in Puerto Rico)

The San Juan coalition formed in response to the *Allies* solicitation. A Puerto Rican-born researcher at the RAND Corp. in California was a key force behind the group. Hence, although the funded work was in Puerto Rico, RAND was the grantee. A researcher at the University of Puerto Rico and personnel at a San Juan hospital and local community development organization were core members of the coalition.

Washington, D.C.: National Capital Asthma Coalition (formerly D.C. Asthma Coalition)

Formed in response to the *Allies* solicitation, the coalition brought together representatives from a number of organizations already working on asthma, such as the local American Lung Association chapter, hospital association and health department.

APPENDIX 5

Strategy Highlights of the Seven Implementation Sites in *Allies Against Asthma*

King County (Seattle), Wash.: King County Asthma Forum

The forum focused its *Allies* interventions on improving asthma prevention, diagnosis and management in low-income, heavily Hispanic neighborhoods of central and southern Seattle and southwest King County.

The efforts included a learning collaborative aimed at improving delivery of pediatric asthma care at four clinics serving low-income patients. Among the other initiatives, multilingual community health workers conducted in-home visits to train families in asthma care and provide case management.

Long Beach, Calif.: Long Beach Alliance for Children with Asthma

The coalition targeted an inner-city zip code with a low-income, ethnically diverse population. Improved coordination of asthma management among families, providers and school personnel was a major focus of the coalitions' work. PACE training for providers was part of that effort. PACE is a training program for primary care physicians designed to improve their proficiency in treating pediatric asthma patients and communicating with their parents. For more information on PACE, see Program Results on ID# 037658.

The group also worked to raise public awareness of the local asthma problem and promote asthma-friendly public policies, especially a reduction of outdoor air pollutants.

Milwaukee, Wis.: Fight Asthma Milwaukee Allies (FAM Allies)

FAM Allies concentrated on central Milwaukee neighborhoods, where many low-income African-American and Latino children with asthma live. The group facilitated in-home education and environmental improvement services, including testing for potential allergens in household furnishings.

In addition, the group sought to educate school and day care personnel on the recognition of asthma symptoms and triggers. Nurse-allergist teams instructed clinicians on improving their asthma management practices.

Norfolk and the Hampton Roads Area of Virginia: Consortium for Infant and Child Health

The consortium's asthma work group focused on improving asthma-related patient care, offering provider and patient education and promoting public awareness of the asthma problem in the Hampton Roads region (which includes seven cities and three counties).

One key initiative was the *Ambassador* program, which used trained individuals from the community to conduct asthma education in the homes of their peers. The consortium also offered PACE and other training assistance for providers.

Philadelphia, Pa.: Philadelphia *Allies Against Asthma*

Focusing on low-income Black neighborhoods in north and west Philadelphia, the coalition worked to improve coordination in what had been for many families a fragmented system of asthma care.

A key component was initiation of the Child Asthma Link Line, a toll-free telephone service that assesses the needs of asthmatic children and their parents and refers families to appropriate sources of assistance.

San Juan, Puerto Rico: Alianza Contra el Asma Pediatrica en Puerto Rico (Allies Against Pediatric Asthma in Puerto Rico)

The coalition focused on improving asthma care for families living in a large, low-cost housing project in the heart of San Juan. The plan included training and deploying housing project residents to identify families with pediatric asthma and link them to a coordinated program of care and support. Asthma management training for school and Head Start personnel and PACE sessions for physicians were part of the effort.

Washington, D.C.: National Capital Asthma Coalition (formerly D.C. Asthma Coalition)

The coalition focused on five zip codes with high rates of hospitalization for asthma among low-income, primarily Black and Latino children. A key objective was to demonstrate how existing health and human services resources could be managed more effectively to achieve measurable improvements in pediatric asthma outcomes.

The action plan included the use of multidisciplinary teams of health and family support workers to target at-risk children. Creation of an electronic data-sharing network to permit comprehensive tracking and management of pediatric asthma cases was another ingredient.

APPENDIX 6

Major Components of the *Allies Against Asthma* Evaluation

The major components of the cross-site evaluation included:

- **Interviews with more than 100 key informants in the seven implementation communities about the coalitions' planning processes, goals, interventions and outcomes.**

  The national program office contracted with Battelle Centers for Public Health Research and Evaluation (a unit of Battelle) to conduct the interviews, analyze the information and report the results.

  The informants included coalition leaders, staff and members as well as local leaders not on the coalition. Battelle conducted two rounds of interviews—in June–September 2003 and again in October 2004–January 2005. The respondents in the first round (110 individuals) and the second round (97) were generally the same individuals.

- **A locally conducted survey of coalition members to assess coalition processes and structure, including coalition functioning, leadership and effectiveness.**

  Each coalition administered a two-page survey instrument—called the *Coalition Self Assessment Survey*—annually in the years 2002–2004. According to the staff, 280 individuals participated out of 400 eligible (a 70 percent response rate).

  Site Project Directors completed additional assessment tools to help the national program staff track each coalition's progress. In addition, the staff interviewed key stakeholders in the local communities, including noncoalition members.

- **A survey of parents and other caregivers to measure the program's intermediate impact on families with asthmatic children.**

  The coalitions individually administered a survey—called the "Core Caregiver Survey"—to a group of pediatric asthma families exposed to the interventions and also to a local comparison group of pediatric asthma families outside the target neighborhoods.

  The survey collected information about the child's frequency of asthma symptoms, hospitalizations and emergency room visits and the caregiver's quality of life and asthma-management strategies. The coalitions administered the survey twice—first to establish a baseline and approximately 12 months later to measure changes. (The coalitions administered the survey on a rolling basis to participants in the intervention group when they started in the program and one year later; they used the survey from May 2003 to 2006).

The national program staff considered the survey a key feature of its assessment of the program's intermediate outcomes.

The national program staff aggregated and analyzed the survey data from five of the seven sites—a total of 849 respondents at baseline (541 from the target areas and 308 from the comparison areas). Respondent loss reduced the total to 542 for the follow-up survey (318 in the target group and 224 in the comparison group).

The staff excluded the San Juan survey results from analysis because the sample size was too large compared to the other sites and would have significantly skewed the results, according to Clark, the program director.

The Washington coalition did not submit survey results. The coalition was unable to fully implement its intervention plan, and did not participate in the survey, the national program staff reported to RWJF.

The two respondent groups were not randomized, but staff adjusted the survey response data to account for differences between the intervention and comparison groups in patient age, gender and other factors that can influence asthma.

Generally, the intervention groups consisted of children whose families received *Allies* in-home visits or other interventions, staff said. Staff noted, however, that it was difficult to ensure a true comparison group. For example, some children outside the target neighborhood could have been patients of physicians who participated in PACE or other *Allies*-generated training.

Each coalition chose its own comparison group, and so the definition differed from site to site. Generally, however, all the coalitions tried to use a local population with demographics similar to the target community's but physically far enough removed to avoid a spillover effect.

- **Collection and analysis of health care utilization data for children in the coalition communities and a set of noncoalition comparison communities.**

  To evaluate the program's impact on asthma-related health outcomes, the national program office initially planned to obtain health care utilization data directly from local hospitals.

  That approach, however, proved impractical. Some hospitals did not have the relevant information or would not provide it, and hospitals willing to cooperate did not all have uniform data, Clark says.

  The staff subsequently entered into an agreement with the federal Centers for Medicare & Medicaid Services (CMS) to obtain zip code-level data on Medicaid-supported hospitalizations, emergency room visits and medication use during the years 1999–2007. The federal Agency for Healthcare Research and Quality (AHRQ) agreed to provide additional hospital usage data.

Transfer and management of the federal data proved a technically complex and lengthy process—and remained ongoing at the end of the RWJF-funded program. The program staff did not expect to receive datasets for the final study year (2007) until 2011.

A $199,954 grant from the W.K. Kellogg Foundation helped fund the data collection and analysis. The grant ended December 31, 2008, and Clark sought additional funding to continue the work. However, she vowed to complete the study using only in-house resources, if necessary.

- **A Web-based, password-protected database—named *Program Reach*—designed to capture and track coalition activities and results.**

  Coalition staff entered the type of activities, the number and type of program participants, topics addressed and settings in which they conducted activities.

- **Identification of the number and types of policy and system changes that the coalitions made either alone or in partnership with other organizations.**

  In fall 2007, the national program staff began distilling a list of policy/system changes from information in:

  — The *Program Reach* database.

  — Interviews with coalition participants/community informants.

  — Written reports by coalition leaders to the national program office and RWJF.

  — Articles published by coalition personnel.

  — Site visit meetings.

  The staff sent the list of items to the respective coalitions for verification, asking the leadership of each to rate—on a scale of 1 to 3—the degree to which the coalition was responsible for each change attributed to it.

  Clark, the program director, said that only changes in which an *Allies* coalition played a prominent part—meaning the coalition either took the major leadership role or was highly visible in the change effort—remained on the final list.

APPENDIX 7

Findings from the Battelle Assessment of *Allies Against Asthma*

- **The time frame—one year for planning and three years for implementation—"proved challenging for all of the coalitions, but all were ultimately successful in engaging members and developing a plan of action…."**
- **"The most significant differences across sites in planning outcomes relate to membership engagement (e.g., type of members forming the coalition core), the intervention strategies selected (e.g., number and relative focus of activities), and the timeline for planning and implementing activities."**
- **"Several important influences emerged on the types of impacts that are being experienced in the *Allies Against Asthma* communities."** These included the intervention mix, length of time for implementation and historical relationships among coalition members.
- **"The *Allies* coalitions are implementing interventions that a single organization either could not do because they lack the credibility or the resources, or would not do because the benefits to them individually would not outweigh the costs."**

  The benefits of working in a partnership—as perceived by participants—include a greater responsiveness to community needs and development of more collaborative and comprehensive interventions.

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- Clark NM, Friedman A and Malveaux, F. "An Introduction to *Allies Against Asthma* and this Special Issue." 8S–12S.
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- Butterfoss FD, Lachance LL and Orians CE. "Building Allies Coalitions: Why Formation Matters." 23S–33S.
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- Lachance LL, Houle CR, Cassidy EF, Bourcier E, Cohn JH, Orians CE, Coughey K, Geng X, Joseph CLM, Lyde MD, Doctor LJ and Clark NM. "Collaborative Design and Implementation of a Multi Site Community Coalition Evaluation." 44S–55S.
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- Clark NM, Friedman AR and Lachance L. "Summing it up: Collective Lessons from the Experience of Seven Coalitions." 149S–152S.
- "*Allies Against Asthma* National Advisory Committee and Staff." 153S–154S.
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Reports

An Exploration of Community Coalitions as a Means to Address Overweight and Obesity. Ann Arbor, MI: University of Michigan, 2007. Available online.

Orians CE, Rose SW and Pearce SE. *Qualitative Evaluation of Allies Against Asthma*. Seattle: Battelle, 2005. (Unpublished report, not for distribution.)

Tools for Assessing Asthma Educational Materials. Ann Arbor, MI: University of Michigan School of Public Health, 2003. Available online.

Survey Instruments

"Core Caregiver Survey," *Allies Against Asthma*, fielded May, 2003 to 2006.

"Coalition Self-Assessment Survey II," *Allies Against Asthma*, fielded May, 2003–October 2003.

"Coalition Survey," *Allies Against Asthma*, fielded July 1, 2003–August 31, 2004.

"Context Surveys Baseline and 1st Follow Up," *Allies Against Asthma*, fielded July 1, 2003–August 31, 2004.

"Key Informant Interview Guides," Battelle Centers for Public Health Research and Evaluation, fielded 2003 and 2004–2005.

"Context Survey," *Allies Against Asthma* National Program Office, fielded, 2003–2005.

"Coalition Self-Assessment Survey III," *Allies Against Asthma*. (The survey instrument incorporates adjustments made for the second follow-up administration by the coalitions June, 2004–October, 2004.)

"Coalition Self-Assessment Survey (CSAS) Context Survey—1st Follow Up Administration," *Allies Against Asthma* National Program Office.

"Final Site Visit Context Interview-Steering Committee," *Allies Against Asthma* National Program Office, fielded 2006–2007.

"Final Site Visit Context Interview-Intervention Staff," *Allies Against Asthma* National Program Office, fielded 2006–2007.

"Final Site Visit Context Interview-Coalition Staff," *Allies Against Asthma* National Program Office, fielded 2006–2007.

Grantee Websites

www.asthma.umich.edu. All about *Allies Against Asthma*, the coalitions and the products. Ann Arbor, MI: *Allies Against Asthma*, University of Michigan School of Public Health, 1999.

asthmaresourcebank.net (no longer available). An interactive website that provided information about asthma-related materials, program tools and instruments. Ann Arbor, MI: *Allies Against Asthma*, University of Michigan School of Public Health. (After *Allies Against Asthma* closed, the national program office transferred the materials to the EPA-supported Communities in Action for Asthma-Friendly Environments Online Network.)

Sponsored Workshops

"Joint Coalition Meeting," June 18, 2003, Washington. More than 60 participants representing coalitions sponsored by RWJF, Centers for Disease Control and Prevention, National Heart, Lung, and Blood Institute and the California Endowment.

"Coalitions for Healthful Living," October 11–13, 2006, Ann Arbor, MI. Attended by 24 people representing the *Allies Against Asthma* coalitions and the national program office. Two presentations, one panel and eight discussion sessions.

PROFILE LIST

Allies Against Asthma: Five Themes

The themes in this Grantee Profile are:

1. Helping Children and Families
2. Changing Physician Practices
3. Empowering the Community
4. Coalitions and Policy Change
5. The Benefits of Coalitions