The Harlem Children’s Zone Asthma Initiative

Angela and Willie Vasquez describe their symptoms differently. “Before it happens I get itchy all over,” says Angela, eight years old. “Then I cough. A lot. And then I can’t breathe. I try to breathe in, but I can’t. My chest feels real tight, like it was squeezed.” “It happens sometimes after I wake up in the morning,” says Willie, Angela’s four-year-old brother. “I’m wheezing, wheezing, wheezing. When I breathe in, it’s not enough air.”

Despite those differences, Angela and Willie agree, emphatically, about the effects of their symptoms.


Angela and Willie Vasquez are among the 31.4 percent of children under the age of 13 in Central Harlem who have asthma. And although their symptoms are severe, and their illness serious, their family feels that the children are fortunate. “We’re lucky,” says Norma Vasquez, grandmother and legal guardian of Angela and Willie, speaking in Spanish through a translator. “We’re in the Harlem Children’s Zone Asthma Initiative now. Last year, the children were in and out of the emergency room all the time. Angela missed 17 days of school. This year, since we’ve been in the Asthma Initiative, she hasn’t missed a single day of school.”

The experience of the Vasquez family is common among participants in the Harlem Children’s Zone Asthma Initiative. A recent Asthma Initiative study published by the U.S. Department of Health and Human Services Centers for Disease Control and Prevention found that the program has been successful in dramatically reducing childhood asthma-related morbidity. The
Asthma is a battle that must be fought on many fronts. How do you do that? I think we found the answer. It's the Asthma Initiative.

Fighting a Battle on Many Fronts

If asthma is widespread across America, it has become epidemic in poor, inner-city neighborhoods. “Some asthma triggers, like pollen and changes in the weather, are common throughout the United States,” says Dr. Vincent Hutchinson, associate director of Pediatrics at Harlem Hospital and medical director of the Asthma Initiative. “But others are much more prevalent in older, urban communities like Harlem—mold; dust mites; the feces of rats, mice, and roaches; overcrowding, which increases the risk of infection. In Harlem, additionally, we have a terrible problem with diesel traffic. Fifteen hundred buses go through Harlem each day; there are five bus depots in the neighborhood. It’s no wonder that asthma is the most common cause of all emergency room admissions at Harlem Hospital.

“In Pediatrics, we have long been aware that the children in Central Harlem have a much higher rate of asthma than children nationally. But there were many things we didn’t know. How much higher was the rate of asthma in Central Harlem? Exactly how many children in our area were affected by the disease? And most important, how could we address the problem most effectively? Asthma is a battle that must be fought on many fronts—the medical front, of course, but also the environmental, social, and even legal fronts. How do you do that? I think we found the answer. It’s collaboration. It’s bringing together the right people, the right institutions, and working together to define and analyze the issues and develop and implement solutions. It’s the Asthma Initiative.”

The remarkable collaboration that was to become the Asthma Initiative began during a breakfast meeting at the Robin Hood Foundation in 2001, where Geoffrey Canada, president and CEO of the Harlem Children’s Zone, met Dr. Stephen Nicholas, director of Pediatrics at Harlem Hospital. The two quickly realized that they shared a deep concern about childhood asthma in Central Harlem. And they recognized the advantages in teaming up to create a new approach to fighting the disease. Within a short time, the HCZ and Harlem Hospital partners also brought in Columbia University’s Harlem Health Promotion Center of the Mailman School of Public Health and Urban Planning Program of the Graduate School of Architecture, Planning, and Preservation; the New York City Department of Health and Mental Hygiene; and Dr. T. Berry Brazelton, one of the country’s foremost pediatricians and child development experts, who was already working with the HCZ Baby College. The Robin Hood Foundation provided the initial funding for the project. That funding has been supplemented by the National Institute of Environmental Health Sciences, the Spunk Fund, and the Dyson Foundation.

“We’ve always been very enthusiastic about this initiative,” says David Saltzman, executive director of the Robin Hood Foundation. “At this foundation, we work on the principle that everyone’s kids should be treated the same way our own kids are treated. My older son has asthma. He gets great care. We wanted that same high level of care for the kids of Central Harlem. And we thought these organizations, working together, were the right ones to find a way to provide that level of care.”

The Asthma Initiative team began meeting regularly to do just that. Each member of the group brought different, and crucial, experience and expertise to the start-up. In broad terms, Harlem Hospital provided medical knowledge and capability; Columbia University supported data collection and evaluation efforts; the city’s Department of Health and Hygiene offered technical assistance on the environmental aspects of the program; and HCZ, with its deep and broad ties to the community, had the means to reach...
out to neighborhood families and involve them in the initiative from the outset. HCZ also brought best-practice experience in community-based interventions to influence the medical model.

“HCZ has an extraordinary degree of credibility inside and outside the Zone,” says Saltzman. “They bring a quality of excellence, and doggedness, to everything they do. There is nobody better. We knew that parents who feared their children had asthma would trust the staff of the Harlem Children’s Zone, as well they should. I know if I lived in the Harlem Children’s Zone, I’d be happy to know that HCZ staff were looking out for my kids.”

Engaging the Family
Family involvement is key to the success of the Asthma Initiative, and every aspect of the program reflects its importance, starting with outreach efforts. The screening survey that identifies neighborhood children who may be suffering from asthma consists of a series of questions to be answered by parents and guardians. When they respond to the questionnaire, the heads of families not only provide vital information, they become, in a sense, participants in the program. So getting the surveys out to families in Central Harlem and then getting those surveys back are critical tasks—tasks that the Harlem Children’s Zone is uniquely qualified to perform.

The 24-block area in Central Harlem encompassed in the original Harlem Children’s Zone Project is home to 13,000 residents, about 2,200 of whom are children 12 years of age and under. With its continuum of community-based programs, HCZ already had in place, at the onset of the initiative, a structure to reach the families of virtually all those children. The Baby College teaches parenting skills to those raising children under three years of age; Harlem Gems is a pre-kindergarten program; and the Harlem Peacemakers, who work in both The Baby College and Harlem Gems, are also stationed in elementary school classrooms throughout the Zone. Through those programs, HCZ staff distributed the screening surveys to families whose children live or attend school in the Harlem Children’s Zone and then often followed up to encourage the families to respond. In addition, The HCZ TRUCE and TRUCE Fitness and Nutrition Center programs helped publicize the initiative through articles in their newspaper, Harlem Overheard, and through a yearly health fair with a focus on asthma. Other means of reaching families included surveillance of Harlem Hospital records and canvassing neighborhood day care and recreational programs.

Out of this extraordinary outreach effort came an extraordinary response from families in Central Harlem. Participation rates for the screening surveys ranged from 62% to 100% at the various distribution sites, with 88% of respondents who were asked consenting to a physical examination of their children. Of the children who were screened, nearly one in three had asthma symptoms—more than five times the national rate.

“No one had ever before done a survey that was this thorough,” says Kate Shoemaker, HCZ director of policy and special projects. “Previously, the top estimates for asthma rates around the country were in the single digits, so we estimated that the rate in Harlem might be as high as 12%. When the real numbers started coming in, we began to get a real grasp of how big the problem was. Fortunately, we had a team that was determined to fashion a solution equal to the size of the problem. One great thing about working at the Harlem Children’s Zone, you’re encouraged to dream big. Well, this was a terrific team on the Asthma Initiative—smart, skilled, and dedicated. All the people and all the institutions involved were totally committed to making one dream come true, the dream of reducing asthma-related morbidity among the children of Central Harlem.”

The first step in realizing that dream was to increase staffing on the project. The childhood asthma rate obtained through the initial screenings was more than twice the rate anticipated; additional personnel were required to meet the increased need. This was especially true because the health-intervention plan...
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determined to have asthma through a medical examination are both invited to participate in the program. Once the family enrolls in the initiative, a community health worker visits the home and completes a baseline assessment.

The baseline assessment helps to determine what each family needs in order to manage asthma more effectively. In some instances, as in the case of the Vasquez family, one of the primary needs was quite basic. “Mrs. Vasquez was unable to communicate effectively with the children’s doctor,” says Sandy Klihr-Beall, the Harlem Hospital pediatric nurse who serves as the clinical coordinator of the Asthma Initiative. “Before they joined the Asthma Initiative, the children had been enrolled in a clinic in Queens, where they lived before moving to Harlem, and where their physician spoke no Spanish. Grandmother speaks almost no English. The children were getting regular medical examinations, and the doctor was aware of their respiratory problems, but the medication they were taking wasn’t working optimally. And the family was unaware of the ways that they could help manage the disease themselves. The treatment of asthma has improved significantly over the last decade. There’s a lot that can be done, and a lot that families themselves can do, to relieve the symptoms of the disease. But before a family can become empowered to manage asthma symptoms, before those symptoms can even be treated properly, there must be real communication.”

After the Vasquez family enrolled in the Asthma Initiative, the children began seeing a Spanish-speaking pediatrician at Harlem Hospital who is on the asthma team. Dr. Benjamin Ortiz soon became the children’s primary physician.

“The children love Dr. Ortiz,” says Norma Vasquez. “I love Dr. Ortiz. He speaks my language. I can tell him myself what symptoms the children have, how they respond to the medication, what seems to cause setbacks or improvements in their condition. He really listens. All the people who work in the Asthma Initiative—the doctors, the nurses, the community workers—they’re wonderful. They’re always there to help whenever we need them. But they also taught us how to help ourselves. That’s been a big difference. Now we know how to manage the asthma. The children are so much better. They’re a lot healthier. They have very few really bad days. They feel like they have more control; they do have more control over the asthma.”

Employing Strategies to Control the Disease

The Asthma Initiative seeks to empower families to help control the disease themselves, in ways consistent with the state-of-the art protocols and practices in asthma treatment. “Today, asthma is viewed and treated as a chronic disease,” says Klihr-Beall. “It used to be that treatment was primarily reactive—open up those airways when they are constricted. Of course you need to do that when someone is having an asthma attack. But the whole point now is to prevent people from having attacks, to reduce the symptoms, to pursue strategies that enable people to manage the disease better. In the Asthma Initiative we employ strategies that we know to be successful in controlling the disease, and we teach those strategies to the families in the program.”

Those strategies are diverse and comprehensive, and they are employed from the very first visit to each family’s home. During that visit, the community health worker talks with family members, gets to know more about the family history and circumstances and the children’s asthma symptoms, and walks through the home to help identify conditions that may aggravate those symptoms. These include well known triggers, such as animal dander, and less obvious triggers, like rugs and stuffed toys. With the information gathered in the first visit, the asthma team can begin customizing the educational and environmental strategies most appropriate for each family—and sharing those strategies with the family.

“We call it Asthma 101,” says Klihr-Beall. “When we visit with the family, we start by explaining what asthma is. I suffer from asthma myself, so I know how frightening an asthma attack can be. We make clear right up front that asthma is a chronic illness, but one that can be monitored, treated, controlled. Then we go through the specific ways that each family, in their own specific environment, can best manage the specific symptoms their children are experiencing. We answer these questions: What triggers an asthma attack? What are the triggers in this home? In this building where the family...
lives? In this neighborhood? What are the best medications to treat the disease? What did the doctor recommend specifically for this child? How do you monitor asthma? What are the warning signs that an attack might be imminent? As we go over all this information with the family, we also develop a specific plan to treat the children in that household. We go over the plan with the family—in great detail. With every visit, we check to see whether the family is following the plan, how well it is working, if it needs to be tweaked. And we do everything in our power, use every means at our disposal, to support the family in putting the plan into action.”

The initiative provides a broad array of support services and materials. To help eliminate asthma triggers in the home environment, families may receive dust covers for mattresses and pillows, HEPA air filters and vacuum cleaners, dehumidifiers, and plastic food-storage containers that discourage pests. In cases where roach, rat, or mice infestation is severe, professional crews can be brought in to eliminate the pests. Medications prescribed by doctors to treat asthma are often administered through “pump” inhalers, which are difficult for young children to use. The initiative provides families with spacer devices that allow children to use their inhalers more easily and effectively. Peak flow meters—small, hand-held devices distributed to families through the initiative—allow parents to monitor their child’s lung functioning daily.

But the primary support for families in the Asthma Initiative are the doctors, nurses, and community health workers who form the asthma team itself. Team members make sure that all elements of the family’s asthma action plan are coordinated; they work with the family to monitor the effectiveness of the plan over time; and they build a relationship of trust and understanding with each family, enabling them to identify and address the entire constellation of issues that have an impact on each child’s asthma.

**Building Relationships**

“There’s an art to this as well as a science,” says Holly Snyder, nurse with the HCZ Asthma Initiative. “You get back a screening survey where there is no formal medical diagnosis of asthma, then you read the list of symptoms that the parent has checked off and you know something is going on. So you invite the family to participate in the initiative. From the first home visit, you have to know what to look for and how to listen to the parents and children. You have to be alert to every way of helping the family, and helping them to help themselves. And your relationship with the family has to be strong enough and good enough so that you can work together productively.”

Snyder works out of the HCZ Asthma Initiative office located in PS 197, on 135th Street and Fifth Avenue, one block east of Harlem Hospital. In daily contact with the children who attend the elementary school, and in frequent contact with their parents, Snyder and the three community health workers at the site have plenty of opportunities to practice the art of asthma management. Their work with the Narain family is a good example of how well they practice that art.

Matthew Narain had experienced asthma symptoms since he was nine months old. “As a baby, he would wake up in the middle of the night wheezing,” says Sunita Narain, Matthew’s mother. “I knew there was a serious problem from the beginning. He would always get much worse in the winter. Cold was a big trigger for him, even air conditioning. He was in and out of the doctor’s office all the time.”

But his doctor never diagnosed Matthew, now six years old, with asthma. To make an “official” diagnosis, doctors sometimes want to see a patient with full-blown asthma symptoms. When Matthew had asthma attacks, his mother would take him to the emergency room. Only later would she bring him to his regular pediatrician for an examination. Another way of diagnosing asthma is through the use of a spirometer, a very precise instrument for measuring lung functioning. But Matthew’s doctor did not have a spirometer in his office. Without an asthma diagnosis, Matthew’s symptoms were being treated with albuterol, a short-term, quick-relief medication that opens up the air passages.

Sunita Narain learned about the Asthma Initiative when she received the screening survey through PS 197. Within a few weeks after she returned the form, the family was enrolled in the program and received their first visit from Serina Moya, community health worker.

“You build a relationship with a family step by step,” says Moya. “It doesn’t happen all at once. You have to show that you know what you’re doing, that you care, and that you have something to offer. It helps if you bring something tangible with you that the family needs. In the first visit, we bring an information...
pack that we leave with the family. In the next visit, we might bring a spacer or a peak flow meter. We bring things people can see and touch and use. That helps them begin to trust us and to understand that we’re working to help them."

Snyder and Moya worked together to help the Narains. During their home visits to the family, Snyder began to notice that Matthew’s symptoms were becoming more severe.

“This winter, we noted that Matthew was having asthma-like symptoms once a day,” says Synder. “When someone has daily symptoms, the asthma-management protocol prescribes that two asthma medications are required. Matthew was only receiving one, a bronchodilator. He needs a long-term medication as well, to manage the chronic condition. So I wrote Matthew’s pediatrician an assessment letter, describing his symptoms and requesting spirometry testing. We just learned that the doctor is purchasing a spirometer. It’s the first step in Matthew’s getting the best medical care.”

In the meantime, Matthew and his family are pursuing other strategies to manage his asthma. With a peak flow meter she received through the initiative, Matthew’s mother began measuring his lung functioning herself. “At first, I didn’t really think it was going to make much of a difference,” says Sunita Narain. “Holly taught us how to use the meter: Matthew blows into it as hard as he can and it takes a measurement. He thinks it’s sort of fun. Then one day the measurement was very low. So I took him to the doctor. And sure enough, he was coming down with a bad cold. Because we had a warning, I had him in bed before the cold symptoms got too bad. He was nice and rested. So he didn’t get a full-blown asthma attack. That made me a believer. Now we use the peak flow meter every day. It’s really helped to keep the asthma under control.”

Once the effectiveness of the peak flow meter was demonstrated, Sunita Narain was more open to employing other strategies suggested by the asthma team. “When Matthew’s symptoms started getting really bad in the winter, Holly explained to me that the standard treatment would probably involve medication that works long-term, for chronic illnesses. I thought, ‘Fine, no problem.’ Then she said that the medication is usually steroids. And I thought, ‘Jose Conseco. Athletes with bulked up arms and bad knees and bones. No way am I putting my child on those drugs.’ But Holly explained that these steroids are not the same as the ones you read about in the paper. She told me the steroids Matthew would be using were safe. Holly explained everything very clearly. I understand what’s she’s saying and I know she’s telling me straight. She and Serina are on our side; they’re looking out for us.”

Snyder and Moya visit the Narains in their home at least once every three months. During those visits, they identified other asthma triggers in the apartment. Because they had gained the family’s trust, Snyder and Moya also got the family’s cooperation in following the asthma action plan they developed to reduce the triggers and control the asthma symptoms. Sunita, Matthew, and Dystiny, Sunita’s seven-year-old daughter, got rid of all the stuffed animals in the children’s bedrooms; began storing dry food in plastic containers they received through the initiative; washed the floors and bathroom tiles with a cleaner containing bleach.

Snyder, Moya, and Sunita Narain have formed, in essence, a partnership to deal with all aspects of controlling Matthew’s asthma. They dealt with the immediate aspects of the illness first, with medical and environmental interventions. Now they are beginning to move on to some of the social aspects of the disease. Stress is a well known trigger for asthma, and the Narain family has had many reasons to feel stress over the last few years. “When I moved to this apartment four years ago, it was to help get away from a domestic abuse
Matthew's asthma better, I can do anything. If I can help make Matthew's asthma much better, I can do anything. They gave me confidence. I've just started looking, but I know I'm going to find a good job. Matthew hardly ever has severe symptoms any more. He's able to do all the normal things kids do. That's the most important thing.

"Once that was under control, I began to look at other things—like myself. Why am I feeling stress and what can I do about it? I realized that I need a job. I want to make a better life for my family. But I didn't even have a decent résumé. So once again, I went to Serina and Holly. Serina helped me put together a really good résumé, and then she used her office computer to help me research job opportunities and start sending that résumé around. What else is really important is that Serina and Holly made me feel like I could really do it. They gave me confidence. I've just started looking, but I know I'm going to find a good job. I feel like, if I can help make Matthew's asthma better, I can do anything."

Knowing How to Win
That feeling of empowerment is hard won. The doctors, nurses, and community health workers of the Asthma Initiative employ a raft of medical, social, and environmental strategies to help families gain the confidence and capacity to control their children's asthma. But sometimes those strategies are not enough.

"Some issues that families in the initiative face require a different kind of expertise," says Kate Shoemaker. "Families facing eviction. Families whose landlords are not patching holes in walls where rodents live or fixing leaky pipes that can lead to mold. Those families require legal assistance. We recognized that early on in planning the initiative. And fortunately, we were able to do something about it. We enlisted the help of VOLS, Volunteers of Legal Services. They not only got lawyers to work with us, they got top-notch Midtown lawyers, lawyers who really know how to win the fights they wage on behalf of our families."

To work with families in the Asthma Initiative, Volunteers of Legal Services recruited the prestigious law firm of LeBoeuf, Lamb, Greene & MacRae. The process through which families access the firm's services is simple and quick. The family is referred to VOLS through a member of its asthma team—doctor, nurse, or community health worker. A VOLS staff member evaluates the request and connects the family with the law firm, and the firm appoints a lawyer with relevant expertise to handle the case.

In spring 2004, Tonya Hill's asthma team referred her to VOLS following an incident at the school of her son Reggie, who was then in first grade.

"Reggie is a very active boy, hyperactive," says Hill. "One day he was running around in school and one of the male teachers tried to restrain him by grabbing him and putting him in a choke hold. It made him very sick. The school called and tried to tell me Reggie had had an asthma attack. I knew that couldn't be true. I'd been in the Asthma Initiative for a year at that time. We used the peak flow meter every day, and that morning he tested fine. When I got to school and Reggie told me what really happened, I argued with the teachers, but they stood by their story. So I went right to Sandy Klihr-Beall. She's Reggie's asthma nurse and she's always been wonderful, helping us with everything. She said I needed a lawyer. And in a few days, I was talking to John Aerni, a lawyer at LeBoeuf, Lamb, Greene & MacRae."

Aerni swung into action immediately. He called the school and requested a written statement describing the event. At Hill's request, he sent letters to the school district and demanded that Reggie be transferred from his current school to PS 11. He arranged for the family to interview at the new school in the summer. By fall 2004, the transfer was completed.

"That's the school I always wanted Reggie to go to," says Hill. "PS 11 is the right school for Reggie, and he's doing very well there. It's all because of John Aerni. He has been very good to us right from the beginning. He's very kind and caring. He invited us to visit his law office and he bought lunch there for Reggie. He called all the time to see how we were doing. I felt like he would help us whenever we needed him, and we did need him again, soon, when we had a housing problem."

In fall 2004, the Hills were facing eviction from their apartment in the Frederick Douglass Houses. Hill, who is unable to work because of debilitating asthma, was having trouble resolving a disagreement with the landlord, the New York City Housing Authority, on her own.
The Asthma Initiative has shown us how to approach complex health issues. This is just the beginning.

“I’ve been living in this apartment for nine years,” says Hill. “For all that time, I’ve been senting in my rent a few days after the first of the month, because I get my SSI check right on the first. I send in the rent as soon as the SSI check is cashed. I kept explaining that to the housing people, but they wrote in my record ‘chronic late.’ Then last summer they mailed me my rent check back and said they were going to terminate my lease. I went and talked to them and explained everything, but they said they couldn’t do anything about it. So I called John Aerni. He called them right up. I don’t know what he said to them, but that was the end of that. No more eviction, no more problems with NYCHA. I think that because we’re low income, they thought they could pressure us out. They thought they could do whatever they wanted. They never thought we had a lawyer. But the minute they found out we had one, they changed. I changed, too. I felt like we can’t be pushed around any more. We’re not alone. We’ve got a whole team of people behind us.”

Participating in the Asthma Initiative has changed John Aerni as well. “This project makes me feel like I’m a part of something great and good,” says Aerni. “The issues we work on through the Asthma Initiative are fairly routine—usually housing, education, and sometimes immigration. But the experience is extraordinary. I believe I get to make a difference in the lives of children, and it’s a wonderful feeling. Some cases get resolved with a single letter whose message is, ‘Please do the right thing. We’re dealing with a child’s health and life here. You can be part of the problem or part of the solution.’ Often people really do want to be part of the solution. And I know why. Because of the Asthma Initiative, I’m a small part of the solution myself, and I’m honored to play that part.”

Improving upon Success

For the last three years, the Asthma Initiative has allowed a large and diverse group of institutions and individuals to each play a part in a comprehensive and extraordinarily successful solution to the problem of childhood asthma. Medical, academic, legal, and nonprofit organizations; doctors, nurses, professors, public health officials, community health workers, administrators; and most important, parents and grandparents, legal guardians, brothers and sisters—every member of families whose children are afflicted with asthma—all play an important, an indispensable, part in the initiative. And because the initiative is so well planned and implemented, the whole is even greater, and more effective, than the sum of its parts.

“The process through which we developed the Asthma Initiative was highly collaborative and very thorough,” says Betina Jean-Louis, Ph.D., HCZ director of evaluation. “The result was no surprise: a program that is collaborative and thorough, in which everyone works cooperatively, if in different ways, toward a single goal. We’re very pleased with the way the project works, and with the results so far. The project is now being rolled out throughout the expanded 60-block area of the Harlem Children’s Zone Project. We’ve screened more than 3,000 children, nearly a thousand of whom have asthma. More than 300 children are enrolled in the initiative, and they are showing remarkable improvements in their condition.

“But we don’t intend to rest on our successes. The different members of the initiative meet with one another regularly and frequently. We are constantly refining the process, constantly making small improvements. We are continually evaluating the whole program and its constituent parts, and we use the evaluations to make changes that make the program work even better. We’re thrilled to see school absences and emergency room visits and hospitalizations go down; but we want those numbers to keep going lower and lower. So we’ll keep improving the program to keep improving those numbers. And we’re not stopping there. We can see that this model works, and we’d like to try it on other health issues, like childhood obesity. These kinds of issues are highly complex, with many contributing causes; but the Asthma Initiative has shown us how to approach complex health issues. This is just the beginning.”

By all accounts, asthma is a very complex disease. And the Asthma Initiative is a complex program. But for the children in the Asthma Initiative, it’s all about something very simple. “Before, I used to be sick all the time,” says Angela Vasquez. “And even when I wasn’t sick, I was worried that I might get sick and have to miss school or go to the hospital. Now I can do everything the other kids do. I don’t worry. I really feel better.” “Me, too,” says her brother Willie. “Really, really, really better.”