

**COMMUNITY ORGANIZING  
STRATEGIES AND CASE EXAMPLES  
IN ADDRESSING ISSUES RELATING  
TO ASTHMA**

**FROM**

**SOCIAL WORKERS MAKING A DIFFERENCE**

**BEST PRACTICES WITH CHILDREN WITH ASTHMA  
AND FAMILIES  
IN URBAN COMMUNITIES**

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## **COMMUNITY ORGANIZING Workshop Overview**

The workshop presenters describe three projects illustrating large scale organizing initiatives designed to address systemic, institutional, and structural conditions that contribute to high prevalence rates of asthma in such City neighborhoods as Central and East Harlem.

### **Building A Community Coalition: A Case Study:**

**Barbara Brenner-Director,  
Community Relations, Mt. Sinai Medical Center**

I have been active in the community for the past 15 years, representing Mt. Sinai in a variety of coalition activities. I am going to talk about the experiences of the East Harlem Health Committee, a highly successful organizing project in the East Harlem community where asthma prevalence rates had reached epidemic dimensions. For example, a prevalence study conducted by the New York Academy of Medicine of two East Harlem public schools showed that 22% of the student body had a diagnosis of asthma. If we had good prevalence studies, the numbers would probably be even higher. The Academy study provided the rationale for developing a strategy for addressing a health problem of enormous magnitude for the East Harlem community.

Creating a coalition to address asthma involved bringing together many community stakeholders. Not only health professionals, social workers, social service providers and community-based organizations, but we knew it would be important to include consumers as well. It would be especially important to include parents because they live the experience of asthma day to day. Establishing the Committee was a long and sometimes difficult process.

**The East Harlem Working Group** was established in 1996 as an outgrowth of the East Harlem Community Health Committee. The Committee was formed in 1970 in response to the threat to close Metropolitan Hospital, which served as a catalyst for mobilizing people across many sectors to oppose the hospital closing. It was a very successful organizing effort, and prevented the closing of the hospital. A smaller group of people from this committee decided to stay together to confront institutional barriers that contributed to disparities in health outcomes for East Harlem residents. The group consisted primarily of representatives from community hospitals and community based organizations. All of us who worked in the community understood the reasons for the poor health status of

the community, despite the presence of three hospitals, two federally funded health centers and many other medical resources, and all kinds of social service provisions in the community. It was related in part to the failure of these groups to develop a means for working together across disciplines, organizational boundaries, and special interests.

Even with all those resources, we were not sufficiently organized to address the serious health problems in the community. The lesson to learn from this is that you may have all of the resources in world at your front door, and still unable to solve a major community problem if there is no well-defined coordinated strategy for making use of these resources.

The East Harlem Health Committee emerged as an initiative to correct this, moving from an issue oriented group that met episodically to become an organized stable group. Over time a stable leadership was formed, and we became a 501(c)(3) non-profit organization with a board of directors, a structure, and with a very clear philosophy and public health mission. Our goal was to rid ourselves of all of the competitive and burdensome attitudes and turfism and see if we could gain consensus as to how problems were to be defined, and then to work together to solve them.

### **The Asthma Working Group**

The East Harlem Health Committee took on a number of different health issues through a committee structure. The **Asthma Working Group** was established in 1996, and emerged from the **Pediatric Health Committee**. Mt. Sinai had consistently provided staff to support this effort since it was the major hospital and medical school involved with the Committee. This was both a benefit and a liability. The benefits were that we were able to draw upon the many resources of the hospital and medical school. The liability is that whenever you have a large institution, a university, a hospital, a medical school, or a large agency, there is the risk that the community agenda may be offset by competing priorities of the larger institution. I find that this is very typical for a medical school. However, although issues have come up from time to time, the Asthma Working Group has been able to work through these to form a strong asthma action agenda that has the support of the Hospital and other community institutions.

The Asthma Working Group is made up of a true cross-section of representatives of

East Harlem. It has brought everyone to the table, which I think is a true test of a coalition. When I say “everybody to the table” I mean elected officials, hospital representatives, social service providers, community health centers, housing organizations, tenant leaders, and representatives of government. Our coalition sought very clearly to bring people to the table from every sector of the community because asthma affects every sector of the community. For example, most East Harlem residents are not home owners. They either rent their apartments from the NYC Housing Authority (NYCHA), or they live in buildings that are privately owned and the landlord is NYC Housing & Preservation Development (HPD). Therefore, representatives from housing organizations, NYC government and tenant leaders needed to be involved.

In the process of undertaking the following activities, the coalition identified a number of gaps in service delivery systems and other critical issues that influence access to health services.

First, we did an inventory of how many programs and services have been created to address asthma in East Harlem. Our initial list totaled 107 separate projects. That number grew to 140 by the time of our final tally. These programs were engaged in a range of activities. Some provided services to prevent asthma, some health education, some case management, and some were involved in some sort of environmental project. We realized that a very clear function of the coalition was to find a way to conduct an analysis of these projects, and devise some sort of plan to evaluate their effectiveness, and integrate these programs to prevent duplication and improve patient utilization rates. The proliferation of agencies established to address asthma, illustrate that asthma was viewed as a health problem of some magnitude for the East Harlem community. However, we had not been able to devise a way to effectively attack the problem.

Second, we endeavored to identify the issues that were most relevant in East Harlem. There was very poor continuity between emergency rooms, primary care providers, schools and parents. There were school rules and regulations that served as barriers to treatment to children experiencing asthma episodes while in school. There was a need for parent education and support. And there was little evidence that children were being taught how to manage their own asthma treatment plans. We also learned that many of the health providers

in the community were not using culturally competent practices and there was a lack of culturally appropriate educational materials.

Third, we realized that although we could focus on treatment and prevention, if we did not take the indoor/outdoor environment into consideration we would get nowhere. We decided to start with the indoor environment of families because poor housing conditions in East Harlem exacerbate asthma triggers. We were able to obtain funding from the Federal Government and the American Academy of Pediatrics to test a home environmental intervention developed as a pilot program. The pilot program was implemented by the Little Sisters of the Assumption. [See Workshop; Asthma in the Home]

The project was a culmination of coalition efforts that brought many community stakeholders together to define a purpose and a problem and then get behind it to secure funding support for a program that addressed the problem. We have also made a submission to the New York City Department of Health and Mental Hygiene that we hope will be approved for \$300,000/year for two years. The money will be used to support coalition activities and a number of discrete projects. Some examples of these are extending the home intervention that has shown to be extremely successful; placing case managers at all of the community health sites; and continuing to test and implement some of the 140 projects identified in the inventory that have proven to be the most effective.

An outstanding challenge that we face is to develop strategies for improving environmental conditions that effect air quality. This will require significant legislative changes in public policy regulating activities like waste disposal and transportation to reduce exhaust fumes from trucks and buses. Our next presenter will discuss these.

**West Harlem Environmental Action, Inc. (WE ACT):  
Peggy Shepard- Executive Director and Co-Founder**

Over the past 14 years, I have worked to impact public policy through community organizing and community-based participatory research partnerships. My organization, West Harlem Environmental Action, or WE ACT, is an environmental justice organization. It was created in 1988 in West Harlem as a result of community organizing around the operations of the North River Sewage Treatment Plant, which is located in the Hudson River between 138th and 145th Streets. A state park had been constructed atop the sewage plant.

I was the Democratic district leader in 1986 when community residents initially asked me to help them organize the community and work to get the City to be accountable for this facility. One of the first things that we realized was that residents were having allergic and respiratory symptoms. The children, some of whom already had asthma, were having asthma attacks more often than usual. We began to make the connection between the facility, air pollution, and asthma. By 1988, we understood our need for data and reached out to Dr. Jean Ford, now chief of pulmonary medicine, at Harlem Hospital.

**Research for Organizing**

We asked Dr. Ford if he observed that more hospitalizations or emergency room visits were coming from specific zip codes near certain facilities like the North River plant. After two years of conducting research, he and his colleagues published a study that indicated that hospitalizations and mortality rates in Northern Manhattan, Harlem in particular, were three to five times those of other communities in New York City. Data from this study armed us with facts to begin more substantive organizing and education of residents around the environmental health linkages. We initiated a strong advocacy campaign targeted to city and state officials around ambient air pollution concerns in Northern Manhattan, pollutants emanating from the plant and the impact on the health of residents. We spent eight years organizing around the North River Plant.

## **Tactics**

Our long-term objective was to place the issue of environmental racism on the City's agenda and to get the plant fixed. Strategies included mobilization, litigation and strong advocacy. We mobilized residents. Between 100 to 200 people came out to meetings around this issue every month. We organized direct action and civil disobedience. On Martin Luther King Jr. Day in 1988, 100 residents participated in civil disobedience demonstrations. Seven of us were arrested holding up traffic during rush hour on the West Side Highway. WE ACT also pursued a legal strategy and filed a lawsuit against the city. We won a 1.1 million-dollar settlement from the lawsuit against the City with the funds being used as an environmental benefits fund for projects in West Harlem. Our advocacy resulted in Mayor Dinkins' commitment of 55 million dollars to fix the North River plant in a five-year plan that ended in 1999. Now the plant is operating more efficiently with less pollution and odors emitted into the community, though children with asthma still may not be safe playing in the park due to the emissions from the plant's stacks that are present in the park.

## **Connecting Issues: "Environmental Racism"**

Community residents began to see that our community was being used as a dumping ground for a variety of polluting facilities and unwanted uses. We call the intentional targeting of communities of color and low income communities for this kind of citing along with the lack of environmental enforcement, "environmental racism."

A prime symbol of environmental racism is the proliferation and expansion of diesel bus depots in Northern Manhattan neighborhoods. Out of the eight depots currently in Manhattan, six are located above 99th Street. There are two in East Harlem, one in Central Harlem, two in West Harlem and one in Washington Heights. These are neighborhoods totaling 7.4 square miles, home to 600,000 mostly African-Americans and Latinos, and home to one-third of New York City's 4,200 diesel buses. Due to ridership demand and the success of the Metrocard, many more buses are being purchased. The MTA is now purchasing or leasing parking lots all over Northern Manhattan to house these hundreds of additional buses. The buses are parked outdoors and not in a heated depot, so those parked buses have to idle all-night so the fuel does not coagulate. The outdoor parking lots have no environmental controls that will trap fine soot particles emitted by diesel buses. These fine

particles exacerbate respiratory disease like asthma and lead to 20,000 premature deaths per year.

The New York State Legislature has focused on this issue and encouraged the MTA to commit to buying more alternative fuel buses and to commit to not building additional diesel bus depots. In addition, the U.S. Environmental Protection Agency (EPA) has promulgated a new heavy duty diesel rule and a new standard for fine particles. However, the same polluted communities will continue to bear this burden over the next ten years until cleaner fuel and vehicles are finally in use and the new regulations have been fully implemented. So, we will continue to have a problem that will affect new generations of children, some of whom, studies indicate, are being born sensitized *in utero* to certain allergens that are triggers for asthma.

Housing is another critical environmental factor. We realized that the asthma belt is the lead belt. The same top ten neighborhoods for asthma are the same top ten neighborhoods for lead poisoning. Housing maintenance is a crucial and unique issue in New York City. This is because 60% to 80% of residents live in rental housing, which means they are not in control of certain aspects of their living situations. They can't control heating, which is often a key trigger for asthma in housing projects where certain lines of apartments are overheated. Tenants can't control moisture. If a toilet overflows upstairs and water seeps into the walls, mold can proliferate. Mold is a trigger for asthma and certain types of mold are highly toxic and can affect neurological function. Mold also results from moisture seeping between the bricks of building facades, which have not been pointed or well maintained. That often happens in NYC Housing Authority buildings as well as privately owned buildings. So, housing maintenance is a critical issue, but it's been very difficult to form coalitions with tenant groups on these issues. However, the New York City Coalition to End Lead Poisoning has been able to coalesce with the New York State Tenants Association. At the neighborhood level, it has been difficult to work with tenant groups because groups have a narrow agenda, few resources, small staff, if any; they feel overwhelmed to take on another issue, even an important one.

### **Organizing to raise awareness**

In 1996, WE ACT began raising awareness around asthma. We joined forces with

the Harlem Health Promotion Center, which is a Center for Disease Control-funded facility that is a project of the Columbia School of Public Health. Ruth Messenger (then Manhattan Borough President) agreed to declare June 1996 as *Uptown Asthma Awareness Month*. We held the first community conference in New York City on that issue. We organized a youth event called “Hoops and Home Runs for Asthma” in a schoolyard where we had physicians like Dr. Jean Ford. We distributed and demonstrated the use of asthma pumps to parents and children and trained them about asthma management. We held a briefing for media and legislators with the Director of the National Institute of Environmental Health Sciences to discuss some of the issues linking asthma and environmental exposures. That’s when we really began organizing at a neighborhood level around asthma.

We have found our partnerships with the Columbia School of Public Health to be very effective and rewarding. We have become a partner in outreach and education; we are also an integral voice in study designs; we are a partner of the Children’s Environmental Health Center at Columbia University.

At the Children’s Environmental Health Center, we are investigating the impact of environmental pollutants and the resulting exposures on pregnant women and their newborn children. Findings indicate that children are being born sensitized in the uterus to certain triggers for asthma. We are following those children and administering developmental tests at six month intervals for a period of two years. One of the published findings is the high level of exposure to pesticides by pregnant women in the study. Many of us have been reading front-page news about the use of illegal pesticides. These are serious exposures taking place indoors as well as in schools. Until recently, parents and teachers were not notified when pesticides were sprayed in schools. You might have a child very sensitive, very vulnerable, yet the parent won’t know what the child is exposed to at school. In the state legislature we have been pushing for a number of “healthy school” bills; a “neighborhood notification” bill on pesticides has recently been passed.

Finally, we have a *Healthy Child, Healthy Home* campaign that WE ACT has organized as a part of our outreach and education response at the Columbia Children’s Environmental Health Center. We have mobilized other community-based groups in Central and West Harlem and in Washington Heights to participate as advisors, and we have

developed training sessions on children's environmental health issues for the health educators employed by these CBO s. We have distributed a tip sheet to parents listing seven key concerns for them to address in their homes regarding pesticides, pest control, children washing their hands, and eating fruits and vegetables. I should also say that organizing is simply a tool, and not an end in itself. WE ACT's eye is on the prize of changing public policy that affects environmental health and community quality of life. To effect change in this arena, we must impact city, state and federal agency regulations, policies and guidelines. But ultimately, change starts with a mobilized, informed community participating in the decisions that affect their quality of life.

### **Northern Queens Health Coalition:**

#### **Mala Desai, Executive Director**

I will focus my talk on what it takes to do community organizing and bring people together to get the work done. My background is working as a volunteer with South Asian women. I started that in 1992 as a volunteer. Within six months, I realized that working as a volunteer with individuals was not going to get South Asian woman anywhere as a group. So, we decided to give ourselves a structure and form an organization. That organization still exists. It is in its sixth year, but still struggling. Hopefully, this year we will have a budget of around \$40,000- our previous budget was below \$20,000. We have survived on donations, relationships and work that we have done with communities across Queens and also at a citywide level.

#### **Building Coalitions**

I am a believer in forming partnerships and collaborations. That is reflected directly in the work I do in my community. Our organization survived because we have formed collaborations with Victim Services Agency and the YWCA in Flushing to start a job placement and training project for women. Of course, when you work with women, it's never work with women alone; so now we are looking to officially revise our mission to include women and families.

Before working with the Northern Queens Health Coalition as a consultant, I had served on the board as a volunteer for almost three years. When we started working with

woman and children, there were needs that woman brought to us that impacted their children, and we realized that we had to look at the bigger picture. So we worked actively with the Northern Queens Health Coalition to form a partnership to begin enrolling children in the new Child Health Plus Program. Fortunately, with the help of the Northern Queens Health Coalition office, we obtained funding in northern Queens for nine separate organizations. These programs are now underway, and we have enrolled almost 100 children in one month among the nine organizations. Working collaboratively, we are ensuring that children receive the health care that they need through the *Child Health Plus Program*.

We put together a committee to seek financial support from the NYC Department of Health for the Northern Queens Region to bring resources for an Asthma Initiative. Immigrant communities have very few resources to provide educational and support services for asthmatic people. The community is also disenfranchised. For example, over 30% of Queens residents are new immigrants who are voiceless and have no political leverage. Unfortunately, our project was not funded. However, one of the funded agencies is a pilot program in Queens named the Center for Children and Families. The program has become a very strong partner in our coalition. In fact, that agency is also the lead agency for the CHIP initiative. So, even though we are competitors, we can also work together for the community that desperately needs service. From this experience, we began a dialogue at the Jewish Community Relations Council again to talk about how to bring partners together who may be competitors but who need to work together to resolve a larger issue in a community.

### **The New York City Asthma Partnership**

I am honored to serve on the Steering Committee of the New York City Asthma City Partnership, and would like to tell you about this initiative. This Partnership has provided me an opportunity to voice the concerns of a number of communities from Queens. It has also helped to create a structure that is needed citywide- one that will be inclusive, reflect diversity and that addresses different points of view. We are in the process of creating that structure with a list of priorities. To do this, we are working with a multitude of stakeholders including hospitals, community-based organizations, The Board of Education, and the Housing Department (HPD). The NYC Asthma Partnership has captured almost every stakeholder in the city that needs to be working together to not only to resolve the asthma

epidemic, but also to prevent future epidemics in the City.

When we organize, it is important to set ground rules and establish a common vision. The vision must reflect and be inclusive of all the resources. I really want to specify that when we developed a vision for the Asthma Partnership, we looked at the wealth of resources that exist within that partnership, including past structures that existed. We also looked at ideology and what it was we wanted the citywide partnership to reflect.

### **American Lung Association:**

#### **Mindy Lieberman, Program Associate**

I work at the American Lung Association in the Public Education and Outreach department. We coordinate asthma education programs on a national level. Our largest program is called **Open Airways for Schools**, which is a school-based asthma education program for third through fifth graders. We work closely with our environmental health department whose main program is called **Indoor Air Quality Tools For Schools**. These are two programs that you can advocate be brought into your school or community. Our government relations department works on a national level to lobby government officials to pass bills that will impact the outdoor and indoor air quality. On a local level, each Lung Association works with geographic communities and local elected official to initiate change.

### **Resources**

There are three different legal tools that an individual or an organization can use to advocate better services for clients.

First, is the *Americans with Disabilities Act*. Although many people are not aware of it, asthma is covered under this Act. It is something that can be used to advocate for services if your clients aren't receiving the proper services either through their health care or through their school services. It's something that you can use with your organization to make sure those services exist for your clients.

Second, there are **two** New York State policies that are important to know about. In New York City, we are in a very unique position because asthma medication is allowed in schools. A law passed under Governor Pataki in 1998, states that a child can bring his asthma medication to school with both physician and parental authorization. One is the

standard MD/parent authorization form created by the Board of Education -- the **504 form**. If your clients who have asthma are unable to bring their asthma medication to school for whatever reason, I would recommend that you research the school's policy. Private schools are under different regulations and may have their own policies. If you are working with a child who has asthma who goes to a NYC public school, it is important for you to be aware of this policy. If you live in another state, you can contact your local Lung Association to find out the policy of taking asthma medications to school in that state. The second NYS policy is *Access to Healthcare*. It is a policy in New York State that provides medical services for the treatment of and rehabilitation with children with disabilities; that includes medical services. There is no reason for a child to go without services. There are free clinics that provide these services. Every child is eligible and should have access to medical services.

The American Lung Association created a resource publication called “**Action on Asthma Binder**.” It includes a list of the laws passed in each state pertaining to asthma as well as guidelines for model legislation. The Binder has language that organizations can use, in collaboration with the American Lung Association, to advocate for bills to be passed.

It is very hard to make changes alone. Working in coalitions can make a difference in your community, especially when using policy as an advocacy tool. I think policy is our strongest ally and we need to really know about it in order to use it. One thing I would like to alert you to is the **resource guide** that was prepared for this conference. It is a resource guide that is comprehensive but by no means exhaustive. It includes health plans and asthma clinics; it has information on nation-wide programs; and pharmaceutical companies where you can obtain free asthma medication. This information can be used as a tool to help your clients get services. As a former direct practice social worker, I know that my resource guide was my “bible” at work. There are so many different programs and services being offered around the city and having a resource guide like this one makes searching for such services a lot easier!

### **Working with coalitions.**

As the newest organizer in this field, it seems like a daunting task to me to start a coalition. It is easy for people to suggest that you should start organizing a group of people

to make change, especially when you are so passionate about a cause. But it can be a really huge task and it sometimes just doesn't seem feasible for a social worker sitting in an office who is trying to help his or her clients day to day. But, what we have learned today is that there are so many resources that the city has to offer and there are so many organizations and coalitions that you can join with in a partnership rather than trying to start something on your own. I am not suggesting that coalitions can't be started, but if there is already a coalition that already exists that is addressing the same issues you are interested in—by all means join it. You cannot only benefit from others' expertise, but you can add your own expertise to that group. I recommend using this resource guide and using the information we learned in this session to help change policy and to change ideas and to change thoughts about asthma and access to care for asthma.