

The Health Politics of Asthma

Environmental Justice and Collective Illness Experience

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Asthma rates have risen so much in the United States in recent decades that medical and public health professionals speak of an epidemic, particularly in urban centers. The number of individuals with asthma in the United States grew by 73.9 percent between 1980 and 1996, with an estimated 14.6 million people reporting suffering from asthma in 1996. This is widely believed to be a real increase, not an artifact of diagnosis (Sears 1997; Woolcock and Peat 1997; Goodman, Stukel, and Change 1998; Mannino et al. 2002). Since then, asthma prevalence rates have reached a plateau, at roughly 7.7 percent of the United States population (22 million) (NCHS 2008b). From 1980 to 2004, hospitalizations for asthma rose 20 percent, and by 2004 there were 1.8 million asthma-related emergency room visits a year. The estimated cost to society from asthma is greater than \$11 billion a year (Pew Environmental Health Commission 2000). As the number of cases has increased, medical and public health professionals and institutions have expanded their treatment and prevention efforts, environmental and community activists have made asthma a major part of their agenda, and media coverage has grown.

The belief in psychogenic causes of asthma, once widely accepted, has given way in the last two decades to a focus on environmental conditions, both indoors and outdoors. Some environmental groups and community activists concerned about asthma have entered into coalitions with academic research centers, health providers, public health professionals, and even local and state government public health agencies to investigate environmental causes. This remains, however, a contentious debate. These disputes, which are important because they influence public health prevention and government regulation, provide fertile ground for the development of the theories and methods discussed so far in this book.

Most public-health education and intervention efforts focus on removing asthma triggers found inside homes, such as mold, roach droppings, and tobacco smoke. These factors are amenable to short-term action that can reduce the frequency and severity of attacks and thus limit emergency room visits. Although public health professionals and organizations also recognize that outdoor air pollution contributes to asthma, they have less capacity to act effectively to reduce it, which involves regulation of emissions and changes in air-quality standards at the local, state, and national levels. Still, many public health agencies and

programs increasingly understand that indoor environmental conditions are related to social inequalities, and they seek an intersectoral approach to improve living conditions, taking into account housing, transportation, and economic development when dealing with health interventions and illness prevention.

Activist groups, which do not provide direct medical and public health services, can place a different emphasis on air pollution. These groups define themselves as environmental justice organizations and view asthma within the larger context of community well-being. They emphasize the unequal distribution of environmental risks and hazards according to race and class and call for the mitigation of environmental factors that they believe are responsible for increased asthma in their communities. Such groups combine general education about asthma with political action to reduce local pollution.

We posit that asthma has become for many people a “politicized collective illness experience,” particularly when community-based environmental justice organizations show people with asthma how to make direct links between their experience of asthma and the social determinants of their health. We are interested less in how the illness shapes the individual experience than in how community-based organizations work to create a collective identity based on the experience of asthma. Collective identity links social and physical realities and tends to be a function of shared grievances that might result from discrimination, structural dislocation, shared values, or other social constructions. Through the process of collective framing, these organizations transform the personal experience of illness into a collective identity focused on discovering and eliminating the social causes of asthma. This collective framing leads to the politicized collective illness experience (see [chapter 2](#)). Changing the perception of asthma by those who suffer from it reveals a new and more empowering path of response.

The approach outlined in this chapter integrates three important areas of medical and environmental sociology—illness experience, environmental justice, and lay discovery of environmental health effects—in order to explore two community environmental-justice organizations working to reframe the etiology of asthma. We begin by pointing out why asthma is significant for health and social policy. Then we examine the social discovery of asthma and its environmental correlates, the political and economic conflicts surrounding asthma research and regulation, and the transformation of the dominant view of the triggers of asthma. Building on those bases, we explore how activist groups have used the issues to build a collective “politicized collective illness experience,” in which people with asthma make direct links between their experience of asthma and the social determinants of their health.

METHODS AND DATA

We focus on two community environmental justice organizations: Alternatives for Community and Environment (ACE) in Boston's Roxbury neighborhood and West Harlem Environmental Action (WE ACT) in New York City. Both have put significant emphasis on asthma education and organizing, and they maintain connections with academic researchers who study air pollution. We see them as influential models of an environmental justice approach to asthma activism. We also include data from our interviews with members of academic and community

partnerships that are funded by one or more federal agencies.

We analyze these cases using content analysis of government documents and scientific literature in medical, public health, and epidemiological journals; sixteen participant-observations of ACE and two of WE ACT by a number of researchers; and twenty interviews with ACE and WE ACT staff, public health practitioners and researchers, and government officials. The ACE observations were mainly conducted at classes taught by ACE in public schools in minority neighborhoods in Boston. These classes provide basic information on the symptoms and environmental triggers of asthma and how to seek help. They also introduce students to concepts of environmental justice and offer them opportunities to get involved in community activism. A few observations were made of other public presentations by ACE staff at conferences and workshops. Observations of WE ACT included spending a day in the organization's office and another day with staff at a New York area environmental justice meeting. Unreferenced quotes come from interviews and observations.

ASTHMA IN HEALTH AND SOCIAL POLICY

The incidence of asthma is significant in the United States for a number of reasons. It has increased dramatically in recent decades; it varies by race and class; it challenges the notion of individual responsibility and focuses on social structural factors; and it leads to pressure on Congress for nationwide health tracking.

Although asthma affects people across all classes and is not restricted to dense urban areas, the poor and minority groups are disproportionately affected. People with asthma are more likely to be children age 5 to 14 years, black, and female (Mannino et al. 2002). In many low-income urban areas, especially minority communities, asthma rates are significantly higher than the national average. Whereas 8.2 percent of all U.S. residents have asthma, 11.1 percent of blacks have the disease (Akinbami and Moorman 2006).

Beyond these already telling statistics, we observed a large degree of community concern about asthma. In many poor and minority neighborhoods, it is one of the most visible and pressing problems residents face. Laypeople have become active in school-based programs, community clinic programs, novel public health initiatives, and activist groups that view asthma as related to social inequalities.

Activism has developed in response to the racial disparities in the incidence of asthma and the attention to air pollution as a trigger. In its focus on environmental and social determinants, asthma activism challenges the view that places the burden of asthma prevention on the shoulders of individuals. Because this approach requires sufferers or their parents to work to remove asthma triggers from their homes, they may feel that they bear primary responsibility for the problem. If their cleanup efforts fail to reduce symptoms, parents can feel responsible for their children's suffering. Moreover, this individual-level approach often obscures the role of corporate pollution and the failure of government regulation.

By contrast, asthma activism takes an intersectoral approach to health. Much can be done to reduce or prevent asthma through nonmedical action in the areas of housing, transportation, and environmental protection. The US Environmental Protection Agency (EPA), National Institute of Environmental Health Sciences (NIEHS), Department of Housing and Urban Development

(HUD), and Centers for Disease Control and Prevention (CDC) have also adopted intersectoral approaches, including funding community intervention programs that have explicit antiracist foundations and that view social inequality as contributing to the asthma epidemic.

For example, the Seattle–King County Healthy Homes Project has focused on improving indoor air quality among low-income families using an explicitly justice-driven model of intervention (Krieger et al. 2002). This project includes elements of community advocacy, in cooperation with the Seattle Housing Authority, in efforts to empower families with the skills, knowledge, and access to care that will improve their living conditions. A similar project, the Southern California Environmental Justice Collaborative (see [chapter 5](#)), also works with communities of color, focusing on the need for a more comprehensive assessment of respiratory health risks that reflects the disproportionate hazard exposure experienced by minority groups (Morello-Frosch et al. 2005b). Likewise, Communities Organized against Asthma and Lead (Project COAL), based in Houston, Texas, brings local community and environmental health organizations together with environmental toxicologists to address asthma triggers in low-income housing (Motosue et al. 2009). Project COAL, like the other two projects, emphasizes the need for empowerment in public health interventions. Thus asthma has become an issue that has mobilized poor and minority people to identify social inequality and engage in widespread political action. Environmental justice approaches to asthma place ethics and rights issues in the center of health policy.

Asthma has been an important impetus behind improved health tracking. The United States has minimal national data-gathering compared to most industrialized nations. Such data are critical to assessing and dealing with asthma because they allow us to better understand inequalities of place (Fitzpatrick and LaGory 2000). Poor and minority people tend to live in areas of higher respiratory hazard exposure. The growth in geographic information systems (GIS) methodologies, the use of EPA's Toxic Release Inventory (a federally mandated reporting system that lists toxic emissions from individual firms, widely used in environmental hazards research), and other such geographically based approaches have increased awareness of place inequality.¹

SCIENTIFIC INVESTIGATION OF ENVIRONMENTAL CORRELATES AND THE POLITICAL RESPONSE

Asthma activists, unlike many other disease sufferers, do not have to fight the government over the effects of environmental factors. Activist, public health, and government actors generally agree on the role of airborne particulates in inducing asthma. However, government efforts to enact stricter air-quality standards have met opposition from industry interests that have challenged both the scientific evidence undergirding new air-quality standards and the government's right to regulate air pollution in general.

Evidence dating back over fifty years suggests a link between asthma and air pollution (Dockery et al. 1993; Amdur 1996; Dockery 2000). Natural experiments have strengthened the evidence linking the two (Pope 1989; Friedman et al. 2001). Less is known, however, about the biological mechanisms that cause asthma and trigger asthma attacks. One study of

schoolchildren in Southern California found that those who exercised outdoors in areas with high ozone concentrations were three times more likely to develop asthma (McConnell et al. 2002). Although recent research focuses on the link between air pollution and triggers of asthma (Barraza-Villarreal et al. 2008; Liu et al. 2009), many investigators continue to search for risk factors for asthma that are prominent in unhealthy residential environments associated with poor and minority neighborhoods (Williams Sternthal, and Wright 2009). As with smoking and its link to lung cancer, sufficient scientific data were not enough to adequately change social policy. Indeed, this failure points to a need for ongoing policy ethnography that allows the effects of science, policy, and activism to be taken fully into account.

The relationship between air pollution and asthma must be seen in light of a wide range of health effects from particulate matter. In total, airborne particulates have been estimated to account for more than 100,000 deaths annually in the United States from pulmonary and cardiac disease—more than from breast cancer, prostate cancer, and AIDS combined (Dockery 2000)—and these findings drive a range of research on the specific health effects of air pollution.

Regulatory standards based on epidemiologic studies have changed considerably over time and remain contentious. The EPA has been only marginally successful in reducing dangerous particulates. In accordance with the 1970 Clean Air Act (CAA), the EPA is required to constantly monitor air quality and to periodically evaluate its air-quality standards. Initially, the EPA regulated only large particles, referring to them as “total suspended particulates.” In 1987, based on new research, the agency revised its standards regulate particulate matter down to 10 microns (μm) in size. In 1994, the American Lung Association filed suit against the EPA for failing to review the air particulate standards every five years as required by the CAA. In response to this pressure and the new evidence of adverse health effects, the EPA again revised its standards to include particulates as small as 2.5 microns in diameter (known as the $\text{PM}_{2.5}$ standard). Industry representatives who feared the high economic costs of reducing particulate matter in their airborne effluent feared the 1997 revisions. Immediately following the signing of the new law on July 16, 1997, a series of lawsuits against the EPA were filed. On May 14, 1999, in *American Trucking Association, Inc., et al. v. U.S. Environmental Protection Agency*, a federal appellate court concluded that the EPA had made unconstitutional delegations of legislative power. Though the appellate decision was a major blow for environmental regulation, in early 2001 the Supreme Court overturned the decision (Greenhouse 2000).

Following the 1997 EPA standard, the National Research Council published the study *Research Priorities for Airborne Particulate Matter*. In response to the claims made in the lawsuits, the study included a comparison of cost estimates with health effects, although the 1970 CAA did not require cost-benefit analyses. According to the EPA, the cost of 15,000 deaths that would be prevented by stricter regulation was higher than the challenger's estimates for the costs of compliance with the stricter standards. Industry critics of the new standards attacked EPA's ability to set the standards once again, this time charging that the EPA relied on “hidden data” and forcing the EPA to ask for a reanalysis of the data by the Health Effects Institute, an autonomous research group jointly funded by the EPA and the automotive industry. The second study reaffirmed the previous findings, but the EPA was forced to compromise yet again and postponed the adoption of the $\text{PM}_{2.5}$ standard until the next five-year review in 2002.

In preparation for the review, the EPA installed thousands of air monitors across the country, strengthening the scientific evidence for the new standard (Greenbaum 2000).

APPLYING THE ENVIRONMENTAL JUSTICE FRAME: ACE AND WE ACT

ACE began in 1993 as an environmental justice organization based in the Rox-bury area of Boston and has since become nationally recognized for its work. One of its earliest actions was a successful mobilization to prevent an asphalt plant from being established in Dorchester. ACE had initially expected to focus on issues such as urban blight, not asthma, but a year of talking to residents showed that they regarded asthma as the most urgent community problem. ACE believes that to reduce asthma rates requires addressing housing, transportation, community investment patterns, access to health care, pollution sources, and sanitation, as well as health education. As one staff member notes, “Everything we do is about asthma.”

WE ACT was founded in 1988 in response to environmental threats to the community created by the mismanagement of the North River Sewage Treatment Plant and the construction of the sixth bus depot in northern Manhattan. WE ACT quickly evolved into an environmental justice organization with the goal of improving environmental protection and public health in the predominantly African American and Latino communities of northern Manhattan. It identified a wide range of environmental threats, including air pollution, lead poisoning, pesticides, and unsustainable development. WE ACT has now extended its reach beyond West Harlem to other northern Manhattan communities.

Combining Social-Structural Approaches with Environmental Justice

Many urban asthma coalitions have developed in recent years to treat, prevent, and educate people about asthma. Some of these programs talk openly about the racial and class inequalities in asthma incidence, pointing to poverty, racism, poor living conditions, inadequate sanitation, and unequal access to health services. They call for housing reform in order to provide living arrangements that will keep children safe from dust, roaches, and poor indoor air. Many people involved in these programs frame their concerns in terms of environmental justice. Several programs train community health workers, reminiscent of the paraprofessional organizations of the 1960s and early 1970s, in which laypeople in the community were taught public health skills (Cohen and Legion 2000).

Despite that broad political understanding, most asthma projects focus on controlling indoor environmental factors. Given the extent of the asthma epidemic, it is understandable that many clinicians, social workers, and community activists want to do front-line work; and rapid interventions to change personal behaviors are often effective in reducing asthma suffering. Yet even if these programs reach a significant fraction of inner-city residents, they cannot offer any protection against air pollution from external sources, both outdoors and when outdoor pollutants enter the home. The Northern California Household Exposure Study has demonstrated the importance of this outdoor-to-indoor pathway (see [chapter 8](#)).

Environmental justice groups, by contrast, focus on sources of outdoor pollution and engage in local, intersectoral political organizing. Their efforts include reducing or eliminating the use

of diesel buses, pressing for stronger air quality regulations, and curtailing hazardous plant emissions. Although some broad national efforts, such as changing air quality regulations, will take a long time, changes in public transportation can be implemented relatively rapidly, resulting in benefits to the entire population. ACE has been able to obtain changes in transit policy, such as controlling truck idling and reducing future diesel bus use. A community-based participatory research (CBPR) partnership between WE ACT and the Columbia University Center for Children's Environmental Health brought about positive outcomes for the West Harlem community, including converting New York City's bus fleet to clean diesel and EPA installation of permanent air monitors in "hot spots" (Vasquez, Minkler, and Shepard 2006).

Transit Issues

ACE encourages communities to take ownership of the asthma issue and to push for solutions. Central to this philosophy is the role of direct action and education, such as a campaign in which residents identified idling trucks and buses as a major source of particulate irritants. They organized an anti-idling march in October 1997 and began giving informational "parking tickets" to idling buses and trucks that explained the health effects of diesel exhaust.

Because ACE identifies diesel buses as a problem, it has taken up transportation issues more broadly. ACE ran a campaign targeting the allocation of transit resources by local and state (Massachusetts) government. Charging "transit racism," ACE argued that the estimated 366,000 daily bus riders in Boston were being discriminated against by the fact that more than \$12 billion of federal and state money was being spent on the "Big Dig" highway project (routing central Boston's arterial traffic through underground tunnels) while the Massachusetts Bay Transit Authority (MBTA) refused to spend \$105 million to purchase newer, cleaner buses and bus shelters. By demonstrating the connection between dirty buses and higher asthma rates, ACE successfully reframed transit spending priorities as an issue of health, justice, and racism. In 2000 the Transit Riders' Union, largely created by ACE, successfully lobbied the MBTA to allow free transfers between buses, arguing that the many inner-city residents who relied on multiple buses for transportation had to pay more than those in other areas who had free transfers on the subway. In the Boston area, buses are more likely to serve inner-city, low-income communities and communities of color, whereas the subway lines serve more affluent communities.

Similarly, WE ACT identified diesel exhaust as a major factor behind the disparate burden of asthma experienced in West Harlem. In November 2000, WE ACT filed an administrative complaint with the federal Department of Transportation against New York's Metropolitan Transportation Authority (MTA), claiming that the MTA advances a racist and discriminatory policy by disproportionately siting diesel bus depots and parking lots in minority neighborhoods. This complaint brought significant public-agency attention to the disproportionate impact of diesel pollution on this community. In addition, using publicity campaigns such as informative advertisements placed in bus shelters, public-service announcements on cable television, and direct mail, WE ACT has reached a vast number of community residents and public officials to let them know that diesel buses can trigger asthma attacks. Though these efforts increased public awareness of WE ACT, and its efforts to improve local air quality reduced asthma rates, the media campaign did not lead to a shift in

New York's Metropolitan Transit Authority's (MTA) policy on regulating and retrofitting diesel buses (Vasquez, Minkler, and Shepard 2006).

Community Empowerment through Education

A key component of ACE's efforts is reflected in its Roxbury Environmental Empowerment Project (REEP), which teaches classes in local schools, hosts environmental justice conferences, and, through its intern program, trains high school students to teach others about environmental health. Classes designed to educate students about environmental justice use asthma as a focal point. For example, REEP teachers discuss the process for siting a hazardous facility in a local neighborhood; they ask the students why such a decision might be made and what they would do about it. Through their "know your neighborhood" strategy, they teach students how to locate on maps the potentially dangerous pollution sources in their community. Experience with REEP has helped some of its high-school interns get into college. ACE also participates in job fairs for students. On some occasions, ACE has brought Harvard School of Public Health air quality researchers to present findings to school audiences. Among other benefits, having research scientists share their relevant work with them demonstrates to children in underfunded and understaffed schools that their health and opinions are valued.

WE ACT's Healthy Home, Healthy Child campaign reflects a similar community-empowerment approach. Although WE ACT has a clean-air campaign in which interested residents are encouraged to participate, the organization believes that focusing solely on air pollution is a disservice to the community. Developed in partnership with the Columbia Center for Children's Environmental Health, the Healthy Home, Healthy Child campaign educates the community about a variety of lifestyle and environmental risk factors, including smoking, lead poisoning, drug and alcohol use, air pollution, garbage, pesticides, and diet, and about actions that residents can take to alleviate or minimize those harms. The campaign began by focusing on specific asthma triggers but soon expanded to include other key concerns such as reducing drugs and alcohol use and improving sanitation services. In addition, empowering local communities entails bringing science to the people. Both ACE and WE ACT have helped communities conduct different kinds of science. ACE's teen interns have conducted local air-quality monitoring, and WE ACT has collaborated with Columbia University scientists to deal with larger-scale pollution emissions.

Organizing with Environmental Justice Principles

Although its work has national implications, ACE's promotion of a new approach to asthma remains expressly local. Like other environmental justice organizations, ACE believes that if it became too nationally focused or too involved in government and academic meetings, it would forsake the individuals in the neighborhood who granted ACE its efficacy in the first place. ACE is aware that even if national PM_{2.5} air quality standards are implemented, local injustices will always require action and redress. Local action can have national significance through action and research by citizen alliances with scientists at research universities. In influencing the way asthma and air particulate research is done, the organizations can shape how the findings are presented and, in some cases, the findings themselves.

Strategies and information can be shared among local groups even without national organization. ACE borrowed the concept of a “transit racism” campaign from the Bus Riders Union in Los Angeles, and WE ACT's challenges to the Metropolitan Transit Authority's bus depot sitings mirror ACE's actions in Roxbury.

Reframing Asthma and Creating a Collective Illness Experience

Organizations like ACE and WE ACT treat asthma as an environmental justice issue and thereby transform the personal experience of illness into a collective identity aimed at discovering and eliminating the social causes of the disease. When people view asthma as related to both air pollution and to conditions in poor neighborhoods, their view of illness changes: their asthma narratives differ from those associated with other chronic illnesses, instead framing the disease in terms of environmental justice, housing, transportation, neighborhood development, the general economy, and government regulations. This broader view is reflected in the goals of one ACE organizer: “I think we have to look at how is it that our society has created such disparate environments for people to live in—from the kind of housing you have, to the kind of school you go to, to the kind of vehicle you ride in, to the kind of air that is outside your door.... I think that there's huge changes that are way beyond individual lifestyle changes that we need to look at about production of synthetic chemicals that may play a role, or about the way we're designing and building our cities, towns, and whatnot.” This outlook enables people with asthma to place responsibility in part on social structural forces.

A common finding in qualitative studies of people with asthma is a feeling of powerlessness. Asthma has no definitive cure: sufferers can rely only on management to prevent attacks. For children, managing asthma requires reliance upon their doctors, parents, and teachers, which reduces their sense of individuality and exploration (Rudestam 2001). Children learn to associate various places with asthma exacerbation, leading many children and their families to associate local environmental hazards with their asthma and experiencing their home and school environments as threatening. When observing a child's difficulty in breathing during an asthma attack, parents themselves may feel powerless. Limited access to health care also leads parents to feel helpless to reduce their child's asthma suffering. Frequent trips to the emergency room are the norm for impoverished families seeking asthma treatment, resulting in both poor disease management and a feeling of loss of control (Center 2000). Not only do they lack access to health care, but they also have little control of either indoor or outdoor sources of asthma triggers.

Community groups like ACE and WE ACT take the position that the medical establishment has a limited ability to address many factors in the experience of asthma, and they see their role as a bridge. One WE ACT organizer described the experience of many people with asthma in a medical setting: “I think that doctors think that there is very little that they can do.... They go through this checklist of risk factors at the beginning of a physical, which now includes, ‘Do you wear seatbelts?’ Like different questions assessing individual behavior and risk-taking behavior. They focus on things that they feel they can change somehow.” Groups like ACE and WE ACT realize that doctors are often unable to address larger issues than individual behavior, this organizer observed: “Even if a kid has really terrible asthma, they're

in the hospital, you know, once every two weeks. Sometimes doctors aren't trained to say, 'Do you have mold in your home—where do you live?' ” They also recognize that even if medical examinations incorporated questions about the home environment, many other important factors shaping the illness experience would still be neglected:

It feels like [asthma] has been taken out slightly from the context of everything else that is happening to people...and I don't think that that is the way that community groups really approach asthma. They see it in the way environment justice sees it, defining the environment where people live, work, play, and breathe. And so it's the underlying conditions of poverty and social injustice that are contributing to all these things. And no matter whose fault it is, you can't just get rid of cockroaches and expect asthma to go away. For that matter, you can't just put in better buses and expect asthma to go away. It's all got to be approached in a social justice framework.

The environmental justice approach to structural factors can change the self-perceptions of people with asthma and hence their illness experience. An essay by a REEP intern illustrates the kind of transformation that ACE can engender in people:

There are things in my environment that truly outrage me. The fact that people have to wait hours for dirty diesel MBTA buses on extremely cold or hot days, the fact that someone I know is being evicted from their home because they can't pay their rent, and the fact that a small child I see everyday has died of asthma in a community where asthma rates are 6 times the state average. These things should not be happening where I live or where anyone lives. Everyone no matter what community they reside in should have the right to a safe and healthy neighborhood. So what is environmental justice is a hard question but I know what it is to me. It is allowing everyone the right to have the best life has to offer from affordable housing to safe neighborhoods and clean air.

Involvement in ACE helped this young community member to draw the connections between a disease like asthma and a wide range of other political and economic circumstances. In painting this broad picture of the causes and experience of asthma, ACE and WE ACT create the foundation for an environmental justice-based approach to reducing the burden of asthma.

Through the educational programs of these organizations, people with asthma learn to manage their disease while beginning to see themselves as part of a collective of people who understand the effects of external factors in contributing to their illness. When they learn that even the indoor air quality in substandard housing is a socially determined phenomenon, they see themselves less as individual sufferers and more as part of a group that has unfair disadvantages. The environmental justice approach tells these people that they can act to change their social circumstances, and in that sense asthma becomes a stepping point to a politicized view of the world. For example, ACE got state, regional, and federal agencies to place an air monitor atop their Roxbury building, with a readout inside the office. They have used this monitor for their educational programs, showing students the relationships between their results on a pulmonary function test and current levels of outdoor air pollution. The ACE

interns and many of the children they teach connect the experience of wheezing with the presence of bus depots and trash incinerators in their neighborhoods.

For a growing number of people and organizations, asthma has been transformed from an individual disease into the basis of a social movement focused on health inequalities. Building and maintaining this social movement is a growing concern for organizers, as noted by an ACE community member: “The other part of ACE that's really emerged probably in the past couple of years is our role as movement builders; building an environmental justice movement both locally and nationally. And the leadership development fits under that as well. But it has changed the way we look at our programs. Now we're trying to figure out how we not only take out interns and train them as educators, but train them as organizers.”

People with asthma in Boston and New York are incorporating rhetoric from the environmental justice movement to address the social and political forces responsible for the disparate rates of asthma among urban minority communities. ACE and WE ACT look beyond medical explanations and solutions to the social forces shaping the urban environment. As one organizer noted: “I think our approach has been that if people are suffering from asthma, that's something we need to deal with now, today. And yes, part of that answer is a medical solution, figuring out how to get people the right treatment. But in the meantime, if there are things we can do to reduce the level of triggers, if we can figure out how to take more a pollution-prevention approach to figure out how to keep these things from getting into the environment, then we ought to do that.”

Through community education and direct-action campaigns, ACE and WE ACT help people with asthma to overcome the stigma that frames asthma both as a weakness and as a result of living in an unclean household. Asthma activists use the destigmatization process to politicize fellow sufferers and gain allies in their effort to produce a healthy environment for their community.

Many people with asthma have arguably developed what we term a “politicized collective illness experience,” in which their personal experiences of illness, symptoms, coping, and adaptation have become linked with efforts to assess societal responsibility for the causes and triggers of the disease as well as responsibility for treatment and prevention.

CONCLUSION

Much attention to the new asthma epidemic comes from laypeople who are concerned about environmental triggers. Their approach to asthma includes action in diverse social sectors, such as housing, transportation, and economic development. Because their view of the disease emphasizes race and class inequities, activists focus on political and economic action. Although they understand the need for attention to triggers in the household, they reject the view that individuals bear primary responsibility for asthma control.

ACE and WE ACT define themselves as environmental justice organizations for which asthma activism is only one aspect of their mission. They represent a unique type of health social movement organization because they are not centered on either a particular disease (as with environmental breast cancer movement groups) or on the health status of a specific group of people (as with the women's health movement). Their efforts show how laypeople's efforts

can reframe health as a social rather than purely medical issue.

Because of the social justice ideology of these movements, which places issues of ethics and rights at the center of health policy discussion, government officials are pressed to pay attention. Asthma activists began with some advantages. They did not have to struggle for recognition of the epidemic: there was ample attention from medical, public health, and educational institutions and professionals, and there was an excellent science base documenting both the prevalence and the triggers of asthma. In addition, although WE ACT and ACE approach science and scientists differently, both groups have found creative ways to work alongside scientists while not placing primary emphasis on a biomedical approach.

In these campaigns, poor and minority people are using asthma rates as indicators of health inequalities. In cases of isolated community contamination, the intersectoral approach taken by asthma activists is difficult to adopt. But as more diseases come to be understood as phenomena linked to modern industrial practices and consumer lifestyles, illness activists stand to learn from the approaches of asthma activist organizations such as ACE and WE ACT.

The growing attention to social and environmental determinants of asthma also fosters a different approach to the illness itself, namely the creation of a politicized collective illness experience. This approach, together with support from public health and science allies, can lead to concrete changes in health policy, especially in terms of health tracking, academic and community collaboration, and stronger air-quality regulation. The Trust for America's Health (formerly the Pew Environmental Health Commission) has pointed to asthma as one of the central reasons why the United States needs a national health-tracking system and has garnered much scientific and government support for this approach. Health tracking involves collecting data that allow scientists to connect rates of disease with a range of factors, including environment, occupation, and lifestyle or behaviors. It also provides information about the rates of disease by geography and ethnicity, revealing whether clusters of diseases are occurring in particular communities or population groups. This combined information can greatly help in the development of strategies to reduce and eliminate disease and lower the cost of medical treatment (Pew Environmental Health Commission 2000). The passage of a 2004 health-tracking bill in Congress led to the National Environmental Public Health Tracking Program, headed by CDC, which funds state departments of public health and universities to develop a national health-tracking network, including the use of existing health surveillance systems and the creation of new biomonitoring initiatives.

Innovative academic and community collaborations, sponsored by federal grants, have developed in recent years, with asthma as a main focus because there are strong community organizations available to do joint work with researchers. And the growing power of the environmental justice activists, combined with much support from public health professionals and a solid base of research demonstrating the harms of airborne particulates, may lead to stronger air-quality regulation.

NOTES

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1. GIS allows the geographic mapping of many kinds of information, allowing researchers to show spatial patterns.