

Pascual, Assistant Secretary for Environmental Justice, California Department of Environmental Quality (March 2003).

10. Models for Change: Efforts by Four States to Address Environmental Justice, "Lessons Learned, Leadership and Accountability," National Academy of Public Administration (June 2002): 1, 119-127

11. The National Academy of Public Administration, for example, recommended that "California's boards, offices, and departments should use the findings from Cal/EPA's examination of existing state legal authorities to advise their staff about the legal options available to address environmental justice." *Ibid.* at 114.

12. Exec. Order No. 12,898, Federal Actions to Address Environmental Justice in Minority Populations and Low-Income Populations, 30 Weekly Comp. Pres. Doc. 279, 280 (February 11, 1994).

13. Solis, like a number of other state representatives who have introduced environmental justice bills, was raised in an environmentally burdened community of color and represents residents in what has been described as an "environmental justice community."

14. SB 115 (1999-00 legislative session), introduced version, cited in Ellen M. Peter, "Implementing Environmental Justice: The New Agenda for California State Agencies," 31 Golden Gate U.L. Rev. 529, 551, note 105 and accompanying text.

15. The third of these provisions, which requires consideration of environmental justice in the permitting of power plants, was enacted entirely outside of the comprehensive approach framework, and is not further discussed. See 2000 Cal. Stat. Ch. 329 § 5. The state legislature has enacted other environmental justice or environmental justice related statutes, more recently, however like the power plants legislation these statutes do not affect the core comprehensive approach initially adopted.

16. See Cal. Pub. Res. Code §§ 72002, 72003 (West Supp. 2001).

17. However, some states, such as Indiana and Rhode Island, have identified additional, specific state entities with which to coordinate, building on existing efforts related to environmental justice.

12

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 that medical and public health professionals invariably speak of asthma as a new epidemic. The number of individuals with asthma in the United States grew 73.9 percent between 1980 and 1996, with an estimated 14.6 million people reporting suffering from asthma in 1996 (Mannino et al. 2002). This is widely believed to be a real increase, not an artifact of diagnosis (Woolcock and Peat 1997; Sears 1997; Goodman et al. 1998; Mannino et al. 2002). In the same period hospitalizations for asthma rose 20 percent, and by 1995 there were 1.8 million 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.

In the midst of this attention, there is significant disagreement over the role of environmental factors in causing or triggering asthma. The widely accepted belief in psychogenic causes for asthma has shifted in the last two decades to a focus on environmental conditions, including indoor ones such as animal dander, cockroach infestation, tobacco smoke, mold, and other allergens; and outdoor ones, particularly PM_{2.5} (particles under 2.5 µm in diameter, which penetrate deep into the lungs and are linked to asthma and other chronic respiratory symptoms, especially among children and the elderly). Some environmental groups and community activists have made asthma central to their work, and in several areas, have entered into coalitions with academic research centers, health providers, public health professionals, and even local and state governmental public health agencies.

Despite grassroots efforts to highlight environmental factors in asthma, this remains a contentious debate; these disputes are important because they substantially influence public health prevention and government regulation.

We argue that asthma has become for many people a "politicized illness experience" whereby 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. Medical sociologists study the illness experience in many ways. They have studied the personal experience of illness and symptoms (Conrad 1987). Others have examined how individuals adapt to their illnesses in order to function in everyday life (Charmaz 1991). Beyond the experience of symptoms and subsequent adaptation, sociologists have also studied how illness shapes personal identity (Bury 1982). Finally, sociologists have studied how individuals search for a cause of their illness and subsequently how they attribute responsibility for the illness (Williams 1984).

In the case of asthma, we are interested in studying not how the illness shapes the individual experience, but rather how community-based organizations forge a collective identity from 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 that is focused on discovering and eliminating the social causes of asthma. This collective framing leads to the politicized illness experience. While our concept of the politicized illness experience is new, it fits well with existing studies by medical sociologists and medical anthropologists on community-based approaches to environmental hazards and catastrophes (Erikson 1976; Balshem 1993) and to collective approaches to illness experience, as with breast cancer (Kasper and Ferguson 2000).

Our approach integrates several 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 envi-

ronmental 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 raised in terms of asthma and the environment to build a collective "politicized illness experience," in which people with asthma make direct links between their experience of asthma and the social determinants of their health.

This linkage of environmental justice and "politicized illness experience" has a strong national impact, since so many EJ groups have pursued asthma as a core concern, and because even asthma programs that do not focus on air pollution take a strong EJ position on the disproportionate impacts of asthma due to poor housing conditions. This linkage can apply to other diseases in which environmental justice activists are concerned with. For example, there has been recent attention by environmental justice activists to lupus, various cancers, and diabetes. Hence, this linkage also offers the potential to build stronger bridges between environmental justice activism and environmental health activism.

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 of which organize around environmental factors in asthma and respiratory health as part of a broader program. We chose these two organizations because they are well-known environmental justice groups that have put significant emphasis into asthma education and organizing, and that maintain connections with academic researchers who study air pollution. We also provide data from our interviews with members of academic-community partnerships that are funded by one or more federal agencies.

Our methods include content analysis of government documents and scientific literature in medical, public health, and epidemiological journals; 16 participant observations of ACE and two of WE ACT; and 20 interviews with ACE and WE ACT staff, public health practitioners and researchers, and government officials. Because much of the organizing and empowerment work of ACE and WE ACT occurs at an informal community level, it

was important to have participant observations that complemented the more direct questioning of a traditional interview process. Interviews and questioning often referenced programs and events that we had observed and allowed us to compare our own observations with the perceptions of participants. The ACE observations were mainly conducted at classes taught by ACE in public schools in nearby Boston neighborhoods. These classes provide basic information on the symptoms of asthma, on how to seek help, and on environmental triggers. 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 to conferences and workshops. Observations of WE ACT included spending a day in their office and another day with them at a New York area environmental justice meeting. Unreferenced quotes come from our interviews and observations.

The Significance of Asthma in Health and Social Policy

Asthma, like most diseases, strikes lower-income populations and populations of color more than other groups. This difference is very pronounced in the United States, though not in the United Kingdom. Although asthma also affects people across all classes, and is not restricted to dense urban areas, the bulk of media and research attention has been focused on low-income people and people of color because they are disproportionately affected by recent increases. Many people of color now report asthma as one of their chief health problems. From 1980 to 1994, asthma rates among children between the ages of 5 and 17 years increased 74 percent nationally, a figure that more than doubles to 160 percent for children under the age of 4 years (Pew Environmental Health Commission 2000). People with asthma are more likely to be children between the ages of 5 and 14 years, blacks compared to whites, and females (Mannino et al. 2002). In many low-income urban areas, especially communities of color, rates are significantly higher than the national average. While national prevalence of childhood asthma in 1997 overall was 7.8 percent for 1-6-year-olds and 13.6 percent for 6-16-year-olds, black children and poor children were 15-20 percent more likely to have asthma (National Health Interview Survey 1997).

Social movement activism has developed in response to the racial disparities in asthma and the attention to air pollution as a trigger. In its focus on environmental and social determinants, asthma activism challenges the individual responsibility approach. Many well-intentioned public health programs understand the importance of outdoor as well as indoor factors. But they usually feel only able to act on indoor factors due to available resources, political constraints, and the fact that indoor solutions appear to provide rapid health effects. Since this involves parents doing a variety of domestic cleanups, people may be left feeling that they are the primary agents responsible for dealing with the problem. Parents can consequently feel responsible for their children's suffering in spite of domestic cleaning regimens. This type of individual-level solution often obscures the role of corporate pollution and government regulation.

Asthma activism advances the environmental justice approach that originally focused largely on demonstrating race and class differences in toxic exposures and proximity to waste sites (Bryant and Mohai 1992; Bullard 1993; Brown 1995). The environmental justice approach has rapidly become central to US environmental policy and includes a Presidential Executive Order to reduce environmental injustice, as well as Environmental Protection Agency programs and guidelines to do so. Further, environmental justice efforts take on a strong intersectoral approach, linking health to neighborhood development, economic opportunity, housing policy, planning and zoning activities, transportation accessibility, sanitation, social services, and education. In this sense, environmental health is a model for intersectoral approaches to health, since so much can be done to reduce or prevent asthma through non-medical action. The Environmental Protection Agency (EPA), the National Institute of Environmental Health Sciences (NIEHS), the Department of Housing and Urban Development (HUD), and the Centers for Disease Control (CDC) have begun intersectoral approaches, including funding community intervention programs that have explicit anti-racist foundations, and that view social inequality as contributing to the asthma epidemic. Asthma has become perhaps the primary disease in which poor people and people of color have pointed to social inequality and have engaged in widespread political action. The case of asthma demonstrates how environmental justice approaches place ethics and rights issues in the center of health policy.

Political Response to Particulate Matter Science

Unlike other diseases, activists concerned with asthma do not have to fight the government concerning the impact of environmental factors. There is much congruence among activist, public health, and government actors on the acute and chronic health effects of air pollution. This is based primarily on the very large and respected body of scientific evidence that supports correlations between air pollution and health effects. Used by federal and state governments to set national ambient air quality standards, the research body represents one of the strongest in environmental health field. For activists, the credibility and strength of this science are valuable tools when addressing air pollution effects with local, state, and federal governments.

However, government efforts to enact strict air pollution standards have been met by opposition from industry interests that politically challenge the scientific evidence undergirding new air quality standards specifically, as well as the government's right to regulate air pollution more generally. Through both lawsuits and political pressure, industry interests have been able to delay the implementation of new air quality standards suggested by scientific research.

Evidence dating back more than 50 years suggests a link between asthma and air pollution (Amdur 1996). Natural experiments such as the closure of steel mills (Pope 1989) or reductions in automobile traffic (Friedman et al. 2001) have temporarily lowered regional asthma rates and strengthened the links between air pollution and asthma. Recent particulate matter research led the EPA in 1997 to set a new standard targeting air particulate matter larger than 2.5 microns (Dockery et al. 1993).

The US government agency responsible for monitoring air pollution and setting air quality standards, the Environmental Protection Agency (EPA), has only been marginally successful in reducing dangerous particulates and has been the target of multiple lawsuits that seek to either implement or delay more stringent air quality standards. 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 Clean Air Act, resulting in the revision of its standards to reduce particulate matter to the 2.5 mg/m³ level in 1997, from the 1987 standard of 10 microns. Industry representa-

tives who feared high economic costs of reducing the particulate matter in their airborne filed a series of lawsuits against the revisions in 1997. Although initially the federal appellate court ruled against the EPA for unconstitutional delegations of legislative power, the decision was overturned by the Supreme Court in early 2001 (Greenhouse 2001).

The lawsuits also questioned the scientific evidence used to set new particulate matter standards, suggesting that the new standards were not cost effective and that the EPA was relying on hidden data. Although independent analyses rejected these claims and supported the 1997 EPA standards, the result was to postpone the implementation of the new standards 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 supporting the PM_{2.5} standard (Greenbaum 2000). (For a more extensive discussion of the scientific literature and the conflicts on regulation, see Brown et al. 2003.)

For activists, the inability of the government to effectively implement and enforce air quality standards can be a source of frustration. Yet despite benefiting from the legitimacy of the scientific evidence for particulate matter health effects, the illness experience continues to be framed in individual terms. Public health professionals and activists believe that not enough has been done to treat and prevent asthma.

Applying the Environmental Justice Frame: Alternatives for Community and Environment and West Harlem Environmental Action

ACE began in 1993 as an environmental justice organization based in the Roxbury-Dorchester 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 permitted in Dorchester. ACE had initially expected to focus on issues such as vacant lots, and did not intend to focus on asthma, but a year of talking with the community showed ACE that residents established asthma as the number one priority. ACE believes that to address asthma 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."

West Harlem Environmental Action (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 working to improve environmental protection and public health in the predominately African-American and Latino communities of Northern Manhattan. They identified a wide range of environmental threats, including air pollution, lead poisoning, pesticides and unsustainable development. WE ACT has continued to grow and expand, extending its reach beyond West Harlem to other Northern Manhattan communities.

Developing a Social Structural, Environmental Justice Approach

It is not easy to develop an environmental justice approach that emphasizes social structural causes of asthma, and to spread that approach to others. Asthma activists have adopted an environmental justice framework that links a discourse of rights and social justice, drawn from the legacy of the civil rights movement, together with mainstream environmental values (Taylor 2000). By drawing on an environmental justice discourse, asthma activists frame the unequal burden of asthma in their communities in terms of inequality, rights, and social justice. For ACE and WE ACT, the environmental justice frame (Capek 1993) is a useful tool for addressing social and environmental causes of asthma.

By linking present conditions to a historical political-economic approach, groups like ACE and WE ACT link the full range of social structural inequalities, including housing, transportation, employment, municipal services, land use, and education. This is the type of approach noted by Pellow (2000). Pellow's environmental inequality model emphasizes the interaction of three methodological and analytical needs: the need to view environmental inequality as a sociohistorical process rather than a discrete event, the need to understand that environmental inequality involves a multiplicity of stakeholders with "shifting interests and allegiances" rather than a simple dyad of victim-perpetrator, and the need to view environmental inequalities as a cyclical process of production and consumption. Pulido (1996: 4-5, 27) views these environmental justice

efforts as "subaltern struggles" in which activists are in "direct opposition of prevailing powers" and are challenging "the entrenched and all-encompassing ways in which power relations are constituted and experienced." The central theoretical insight offered by Pulido's approach is that subaltern struggles over environmental issues are never solely about the environment. Subaltern struggles call into question forms of structured inequality and directly challenge these institutionalized forms of domination. Many urban asthma coalitions have developed in recent years to treat, prevent, and educate around asthma. Some of these asthma programs openly talk 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 better 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; these programs are reminiscent of the 1960s and the early 1970s, when laypeople in the community were taught considerable public health skills in order to have them carry out intervention work in a culturally/racially/ethnically appropriate way (Cohen and Love 2000).

Despite that broad political understanding, most asthma projects focus on controlling indoor environmental factors. In view of the extent of the asthma epidemic, it is understandable that many clinicians, social workers, and community activists want to do front-line work to achieve rapid changes in personal behaviors, which are often effective in reducing asthma suffering. But even if these programs reach a significant fraction of inner-city residents, they cannot prevent outdoor air pollution from remaining hazardous (both outdoors and when it enters the home).

This is where the environmental justice groups come in. They focus on sources of outdoor pollution, and engage in local-level intersectoral political organizing. This includes reducing or eradicating diesel buses, pressing for stronger air quality regulations, and curtailing hazardous plant emissions. While some broad national efforts, such as changing air quality regulations, will take a long time, local changes in public transportation can be relatively rapid, resulting in benefits to the entire population.

Transit Issues

ACE encourages communities to take ownership of the asthma issue and to push for proactive, empowered solutions. Central to this 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 and began giving informational 'parking tickets' to idling buses and trucks that explained the health effects of diesel exhaust.

Since ACE identifies diesel buses as a problem, they also take up transportation issues more broadly than just air pollution. ACE ran a major campaign targeting local and state government over the allocation of transit resources. Charging "transit racism," ACE argued that the estimated 366,000 daily bus riders in Boston were being discriminated against by the over \$12 billion of federal and state money being spent on the "Big Dig" highway project, while the Massachusetts Bay Transit Authority (MBTA) refused to spend \$105 million to purchase newer, cleaner buses and bus shelters. In tying dirty buses to higher asthma rates, ACE successfully framed an issue of transit spending priorities into one of health, justice, and racism. In 2000 the Transit Riders' Union, largely created by ACE, got the MBTA to allow free transfers between buses, since the many inner-city residents who relied on two buses for transportation had to pay more than others who had free transfers on subways.

Similarly, WE ACT has identified diesel exhaust as a major factor behind the disparate burden of asthma experienced in their community. Using publicity campaigns such as informative advertisements placed in bus shelters, public service announcements on cable television, and a direct mailing, WE ACT has reached a vast number of community residents and public officials and let them know that diesel buses could trigger asthma attacks. Though their efforts increased public awareness of WE ACT and its efforts to reduce asthma, the media campaign did not lead to a shift in New York's Metropolitan Transit Authority's (MTA) policy toward diesel buses. In November 2000, WE ACT filed a lawsuit against the MTA with the federal Department of Transportation claiming that the MTA advances a racist and discriminatory policy by disproportionately siting diesel bus depots and parking lots in neighborhoods with people of color.

Community Empowerment through Asthma and Social Education

A major component of ACE's education and empowerment efforts is reflected in its Roxbury Environmental Empowerment Project (REEP). REEP teaches classes in local schools, hosts environmental justice conferences, and through its intern program trains high school students to teach environmental health in schools. Classes are designed to educate students about environmental justice, and use asthma as a focal issue. For example, REEP teachers discuss the potential process for siting a hazardous facility in people's neighborhoods, and ask the students why was this being sited there, and what would they do about the siting decision. Through their "know your neighborhood" strategy, they teach students how to locate on local maps the potentially dangerous locations in their area. ACE has helped some of its high school interns get into college as a result of the education they received in the REEP program. ACE also participates in job fairs to help students find good employment prospects. On some occasions, ACE has brought Harvard School of Public Health air quality researchers along with them, to present findings to school audiences. In this way, ACE demonstrates to children in underfunded and understaffed schools how important they are, by having important scientists share their relevant work with them.

WE ACT's Healthy Home Healthy Child campaign reflects a similar community empowerment approach. WE ACT works to address a broad range of issues and does not attempt to separate environmental issues from each other or the community context. The Healthy Home Healthy Child campaign, developed in partnership with the Columbia Center for Children's Environmental Health, works to educate the community on a variety of risk factors including cigarettes, lead poisoning, drugs and alcohol, air pollution, garbage, pesticides, and nutrition. Educational materials, translated both from English into Spanish and from medical terminology into lay language, inform residents about the effects of risk factors and actions they can take to alleviate or minimize those effects. In the case of air pollution, one of the actions that residents can take is to contact WE ACT and become involved in their clean air campaign. WE ACT believes that focusing solely on air pollution can be a disservice to the community and thus it addresses all of the issues raised in the Healthy Home

campaign. As with ACE's experience in identifying community issues, WE ACT's Healthy Home Healthy Child campaign began by focusing on specific asthma triggers, but soon expanded to include such concerns as drugs, alcohol, and garbage.

Approaches to Scientists and Academic-Community Collaboration

ACE's use of an environmental justice frame means that the organization is not wedded to the procedures and science of public health. They see that other groups have gotten entangled organizationally in complicated scientific debates over statistical significance and epidemiology that can last many years. At the same time, ACE understands the need for scientific evidence and scientific legitimacy, recognizing the long-term importance of establishing links between air pollution and asthma. ACE's decision to work selectively with science, and to insist on the role of science in empowering community residents, is central to their asthma work. Hence, they use science as a tool in the larger arsenal of political and social movement tactics.

Support from some researchers at the Harvard School of Public Health and the Boston University School of Public Health provides an opportunity for ACE to work with science in its own way. ACE's AirBeat project monitors local air quality and then analyzes the relationship between air quality and medical visits. ACE mobilized researchers and government agencies to install a monitor at their Roxbury office. Community members are also directly involved in the planning and implementation of these studies, as evidenced by the involvement of REEP students in identifying data types to be collected from community clinics. On one level ACE collaborates with scientists to produce quantifiable outcomes they hope will lead to greater understanding of air pollution and asthma. This has resulted in jointly authored articles on air particulate concentrations, published in major environmental health journals. However, AirBeat is useful in other ways as well. ACE derives legitimacy from the involvement of government agencies and scientists in the process, such as the presence of Harvard scientists and the then-EPA Region 1 head John Devillars at the press conference when the air monitor was unveiled.

WE ACT has been much more eager than ACE to work together with university-based scientists. They are partners with Columbia University

School of Public Health in a federally funded project on collaborative academic-community research and advocacy. They have published numerous papers in scientific journals, and in 2002 edited a Supplement of the prestigious *Environmental Health Perspectives* on "Community, Research, and Environmental Justice" (which contained an article by ACE staff members). WE ACT also coordinates conferences that bring together activists and scientists to consider pressing ethical and policy concerns. Both ACE and WE ACT believe they are pushing their scientific allies to be continually more community-oriented in defining problems and designing research and interventions.

Organizing with Environmental Justice Principles

While working with scientific collaborators to improve our understanding of the link between asthma and air pollution may promote stricter federal regulations, ACE and WE ACT are dedicated to improving local environmental conditions. Environmental justice organizations like ACE and WE ACT are rooted in grassroots activism that is very community oriented. Although their work has national implications, ACE's promotion of a new approach to asthma remains expressly local in focus. Like other grassroots environmental justice organizations, ACE believes that if it becomes too nationally focused or involved in too many governmental and academic meetings, it would forsake the individuals in the neighborhood that have granted ACE the efficacy in the first place. ACE is aware that even if there is national implementation of safer PM_{2.5} air quality standards, local injustices will remain, and hence local action will always be necessary. Local action can have national impact based on the accumulation of action and research by citizen-science alliances involving national-level research universities. In influencing the way this science itself is done, the organizations can shape how the findings are presented, and in some cases, the findings themselves. Additionally, limited national networking encourages community-based organizations to use other groups' issues and strategies—ACE borrowed its 'transit racism' campaign from the Bus Rider's Union in Los Angeles, while WE ACT's current challenges to the Metropolitan Transit Authority's bus depot sitings mirror ACE's actions in Roxbury. Thus, strategies are shared, even if there is no national organization.

This environmental justice approach relies on community-level organizing and empowerment to respond to structural factors. But the same approach also has ramifications for internalized self-perceptions of people with asthma, and hence for their illness experience. Part of the rationale for ACE's and WE ACT's efforts to change social perceptions of asthma causation is to simultaneously transform the self-perception of people with asthma. One of the REEP interns wrote an essay in which he characterized the kind of transformation that ACE engenders 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.

Thus, ACE's environmental justice frameworks allow the student to see their individual lived experience in the context of a larger set of structural factors and injustices, and thereby empowers them to participate in community changes, rather than marginalizing and isolating their experiences.

Reframing Asthma and Creating a Collective Illness Experience

As was mentioned earlier, we are not examining how asthma shapes individual illness experience, but rather how activist groups create a collective identity around the experience of asthma. These organizations collectively frame asthma as an environmental justice issue, and therefore transform the personal experience of illness into a collective identity aimed at discovering and eliminating the social causes of asthma. When people view asthma as related to both air pollution and to the living conditions of poor neighborhoods, they reconstruct asthma narratives differently than the narrative reconstruction that occurs with other chronic illnesses. Because asthma is increasingly framed in the language of air pollution and environmental justice, the disparities in asthma suffering are translated into the rhetoric of illness experience. Illness experience in the case of asthma is broader than that of the typical illness narrative. Such narratives typically incorporate

perceived causes and effects of the disease with personal perception, work, family, relationships, and schooling. But asthma activists also include the political economic framework surrounding the production of asthma and the political perspectives that situate asthma in terms of housing, transportation, neighborhood development, the general economy, and government regulations. This broader focus on the social and economic factors shaping the illness experience of asthma 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 enables people with asthma to place responsibility in part on social structural forces.

The experience of illness plays a major role in the educational programs conducted by ACE and WE ACT. Because ACE, WE ACT, and various academic-community partnerships hold so many educational sessions to make asthma a very public concern, the stigma and denial normally associated with asthma is lessened. A common theme to emerge from qualitative studies of people with asthma is the feeling of powerlessness. Both among children and adults, people with asthma are without a potential cure for the disease and 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 (K. Rudestam et al., "Children's Asthma Experience and the Importance of Place," *Health* 8, 2001: 423–444). Children learn to associate various places with asthma exacerbation, leading many children and their families to associate local environmental hazards with their asthma. When observing a child's asthma attacks, parents themselves may feel powerless to help their child breathe normally. Limited access to quality 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 management and the loss of control (Center 2000). Inequalities in health polarize the experience of

asthma in terms of agency. For children and their families who cannot afford quality management of the disease, asthma becomes another problem beyond their control, exacerbating the feeling of powerlessness. Not only do they not have adequate access to health care, but they have little control of either indoor or outdoor sources of asthma triggers.

Community groups like ACE and WE ACT work to reframe the illness in terms of the larger illness experience. They feel that the medical establishment has a limited ability to address many of the important factors in the experience of asthma, and see their role as a bridge. One WE ACT organizer recounted the experience many people with asthma go through in a medical setting:

I think that doctors think that there is very little that they can do about [the factors of asthma]. 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. So they ask about the indoor environment.

Groups like ACE and WE ACT realize that doctors are often unable to address larger issues than individual behavior, as an ACE activist pointed out:

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 ask "Do you have mold in your home? Where do you live?"

Organizers at ACE and WE ACT also recognize that even if the medical community incorporated questions about the home environment, many other important factors shaping the illness experience would still be neglected. As an ACE staff person noted:

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 environmental 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.

As the above perspective indicates, public health and transportation interventions can be helpful, but there are nevertheless overarching social inequal-

ities that will continue to yield disproportionate exposure and disease unless the core social structure is altered. In painting this broad picture of the 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 held by ACE and WE ACT, people with asthma learn to manage their disease while simultaneously beginning to see themselves as part of a collective of people with asthma who understand the importance of external factors beyond their individual homes. By learning that even their indoor exposures through poor housing are a social phenomenon, they see themselves less as individual sick people and more as part of a group that has unfair disadvantages. The environmental justice approach informs 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 in their Roxbury office. They use this monitor for their educational programs in public school and community after-school 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 cannot separate out their experience of wheezing from their knowledge of the harmful effects of diesel exhaust from nearby buses. They cannot think about their inhalers without thinking about the excess of bus depots and trash incinerators located in their neighborhoods.

For a growing number of people and organizations, the experience of illness has transformed asthma from an individual disease into a social movement focused on health inequalities. Their role in building and maintaining this social movement is a growing concern for organizers, as noted by this ACE organizer:

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.

Based on the illness experience we have described above, we believe that many people with asthma have developed what we term a "politicized illness experience," in which their personal experience of illness, symptoms,

coping, and adaptation has become linked with a broad social critique. This critique involves assessing responsibility for the causes and/or triggers of the disease, as well as responsibility for treating and preventing the disease. The use of an environmental justice discourse frames ACE and WE ACT's activism in terms of social justice that has both local and national components. On the local level, ACE and WE ACT are directly involved in improving the living and working conditions of community members who suffer from asthma. By addressing transit issues and other socially structured forms of environmental inequalities, ACE and WE ACT are able to address local environmental problems. At the national level, the organizations have been able to establish collaborative scientific endeavors to improve our understanding of the relationship between asthma and air pollution. These collaborations between activists and scientists also advocate for social justice through their focus on outdoor source of air pollution rather than indoor causes (which places the burden of responsibility on the individual). Thus the politicized illness experience links the local burden of disease together with broader social factors, which in the words of an asthma activist is working toward "building an environmental justice movement both locally and nationally."

Conclusion

As we have shown, a considerable amount of attention to the new asthma epidemic comes from laypeople who are concerned with environmental factors as triggers. Their broad intersectoral approach to asthma includes action in diverse social sectors, such as housing, transportation, and economic development, and is framed in environmental justice terms that emphasize race and class inequities. The environmental asthma activists focus their attention on political and economic action. Although they understand the need for household level attention, they reject the primacy of individual responsibility for asthma control.

ACE and WE ACT exemplify this environmental asthma approach, and define themselves as environmental justice organizations for which asthma activism is only one part of a broader approach. Even though they are not primarily health-oriented, they offer a sociologically informed approach to disease. This type of wide-reaching approach to social health, rather than

just medical health, provides an important insight into new ways that lay-driven efforts can reframe social conceptions of health.

This environmental focus on asthma has achieved legitimacy in part because of its health inequalities and environmental justice approach. Because of its express social justice ideology that places issues of ethics and rights in the center of health policy discussion, government officials are pressed to pay attention. Activists' legitimacy was enhanced by not having 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. In addition, although WE ACT and ACE approached science and scientists differently, these groups have found creative ways to work alongside scientists, while not placing primary emphasis on research.

Asthma has become perhaps the primary disease in which poor people and people of color have pointed to social inequality, and it is a useful class and race indicator of health inequalities. The wide-ranging, intersectoral perspective we see in environmental asthma activism offers lessons for future contested illnesses. In cases of isolated community contamination, the intersectoral approach is difficult to adopt. But as more diseases come to be understood as widespread 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.

Further, the growing perspective on social and environmental determinants of asthma fosters a different approach to personal illness experience, what we term a politicized illness experience. We expect this politicized illness experience, together with support from public health and science allies, to lead to concrete results in health policy, especially in terms of health tracking, academic-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 governmental support for this approach, including recent passage of a health tracking bill in Congress. Innovative academic-community collaborations sponsored by federal grants have developed in recent years as well, with asthma a main focus because there are such strong community organizations available to do joint work with

researchers. Last, the growing power of the environmental justice activists, combined with much public health sympathy toward the environmental justice perspective and with a solid science base of particulate researchers, holds the potential to support stronger air quality regulation.

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13

Whose Environmental Justice? An Analysis of the Governance Structure of Environmental Justice Organizations in the United States

Robert J. Brulle and Jonathan Essoka

To be able to satisfy these functions in the sense of democratic opinion and consensus formation, [a social movement organization's] inner structure must first be organized in accord with the principle of publicity and must institutionally permit an intraparty or intra-association democracy to allow for unhampered communication and public rational-critical debate.

—Jürgen Habermas (1962: 142)

The means by which citizens act together to pursue their common interests has long been a topic of intellectual inquiry and practical politics. The important potential role played by civil society in the maintenance, legitimacy, and stability of democratic society has been recently examined by a number of authors (e.g. Skocpol 2003; Barber 1984; Calhoun 1993; Habermas 1984, 1987, 1991, 1996; Putnam 2000; Fiorina and Skocpol 1999; Fung 2003). Civic organizations, based in civil society, are seen as a critical link in translating the impulses from everyday experience into political demands for change (Habermas 1987, 1998). The core idea is civil society forms an autonomous site independent of the market economy and the state, providing citizens with the opportunity to freely associate, develop an ethical life and exercise their citizenship. Thus civic associations form an important site for the creation and maintenance of a democratic society (Skocpol 2003; Clarke 2001). This puts civic associations at the center of the renewal and transformation of social institutions, including the transition to an ecologically sustainable society.

Thus, how environmental movement organizations are governed has important consequences for the viability of this movement. First, to enhance and strengthen the democratic nature of civic life of the communities in which these organizations work, it is important that they have open and