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## “Complexities of holistic community based participatory research for a low-income, multi-ethnic population exposed to multiple built-environment stressors in Worcester, Massachusetts”

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### Abstract

Low income, multi-ethnic communities in Main South/Piedmont neighborhoods of Worcester, Massachusetts are exposed to cumulative, chronic built-environment stressors, and have limited capacity to respond, magnifying their vulnerability to adverse health outcomes. “Neighborhood STRENGTH”, our community based participatory research (CBPR) project, comprised four partners: a youth center; an environmental non-profit; a community based health center; and a university. Unlike most CBPR projects that are single topic-focused, our ‘holistic’, systems-based project targeted five priorities. The three research-focused/action-oriented components were: 1) participatory monitoring of indoor and outdoor pollution; 2) learning about health needs and concerns of residents through community based listening sessions; and 3) engaging in collaborative survey work, including a household vulnerability survey and an asthma prevalence survey for schoolchildren. The two action-focused/research-informed components were: 4) tackling persistent street trash and illegal dumping strategically; and 5) educating and empowering youth to promote environmental justice. We used a coupled CBPR-capacity building approach to design, vulnerability theory to frame, and mixed methods: quantitative environmental testing and qualitative surveys. Process and outcomes yielded important lessons: vulnerability theory helps frame issues holistically; having several topic-based projects yielded useful information, but was hard to manage and articulate to the public; access to, and engagement with, the target population was very difficult and would have benefited greatly from having representative residents who were paid at the partners' table. Engagement with residents and conflict burden varied highly across components. Notwithstanding, we built enabling capacity, strengthened our understanding of vulnerability, and are able to share valuable experiential knowledge.

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Human subjects review and approval: We obtained Clark University Institutional Review Board (IRB) approval for the work and informed consent from all research participants.

## Keywords

environmental justice; built environment; vulnerability; community based participatory research (CBPR)

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## INTRODUCTION

In our rapidly urbanizing world, growing geographical disparities between affluent and impoverished human habitats are a disturbing trend that implies increasing inequality and social injustice, deteriorating social order, and a disproportionate environmental health burden for the poor (Massey 1996). Links have been shown between low socio-economic status and increased exposure to environmental risk factors (Evans and Kantrowitz 2002). Among people who inhabit urban areas where pollution, crime, violence, and social disorder are major stressors, a persistent sense of powerlessness and fear can adversely impact both mental and physical health (Ross and Mirowsky 2001, Geis and Ross 1998).

Vulnerability to stress is a function of exposure to stressors coupled with the capacity to respond, cope or adapt (NEJAC/EPA 2004, Ahmad et al. 2001). Responding involves either reducing the probability of an adverse outcome and/or the severity of the outcome should it occur. Since vulnerability is a function of exposure to stressors and adaptive/coping capacity it links directly to the need for capacity building (Downs 2007). Using a coupled CBPR-capacity building approach allowed us to identify and tackle agreed-upon issues. Vulnerability theory also allows us to contemplate multiple, nested scales of relevance: individual, household and neighborhood/community. Four aspects influence vulnerability at these scales: 1) differential exposure to stressors; 2) differential susceptibility and sensitivity to adverse outcomes if exposed (*susceptibility* relates to predisposition of outcomes occurring if exposed; *sensitivity* to how probability and degree change with changes in exposure); 3) differential preparedness to respond; and 4) differential 'coping', 'resilience', 'adaptability' or ability to recover from impacts (after Ahmad et al 2001, NEJAC/EPA 2004). These four aspects shaped the design of a household vulnerability survey tool, the application of which became the main action-oriented research activity.

One of the most important coping/adaptive capacities in stressful urban environments is the building of *social capital*: systems of interaction, resource sharing and communication among different individuals and groups who would otherwise be isolated. Community based participatory research (CBPR) helps build social capital, and strengthens adaptation. CBPR has an important role to play in increasing our understanding of stressful environments (stressors and health outcomes), and the multiple ways to respond to them: building adaptive/coping capacity, and changing policies and practices to reduce exposures to stressors. CBPR draws heavily on participatory models (Israel et al. 1998, Minkler and Wallerstein 2003, Fawcett et al. 1995), and promotes the active involvement of communities in the shaping of research and intervention, and the conduct of research projects (O'Fallon et al. 2000).

CBPR offers distinct advantages over traditional positivist scientific research: 1) it can ask and sometimes answer questions about environment and health that matter to the people who bear the burden of adverse environmental health outcomes (Northridge et al. 2005); and 2) it can help build the requisite collective capacity among residents-at-risk, CBOs, public health agencies, policy makers and scientists to respond to priority problems with strategic, cost-effective and sustainable changes in policies and practices (Downs and Larson 2007). The increasing traction of CBPR-based projects is a reflection of growing awareness about the limitations of traditional biomedical approaches to both explain and adequately address health disparities, especially in marginalized populations. Understanding of socio-cultural, political,

economic, and ecological vulnerability factors – as well as personal factors (age, gender, genetic predisposition) - is needed to explain and address health disparities (Kawachi and O'Neill 2005, Corburn 2004, Lebel 2003, among many), and to move towards strategic prevention and treatment combinations tailored to each context (Downs and Larson 2007). To date, much CBPR work has been driven by “hot-button” issues like landfills or polluting industries. Yet most built environments where low income, multi-ethnic or minority communities live lack galvanizing issues: residents are exposed to cumulative, chronic built-environment stressors, and have limited capacity to respond, magnifying their vulnerability to adverse health outcomes. The Main South/Piedmont neighborhood of Worcester – our own local community and study area - is a place of such ‘everyday environmental injustice’, demanding a more holistic approach.

The purpose of this paper is to share the experience, knowledge and lessons learned from our own CBPR project: “Strengthening vulnerable communities in the Worcester built environment” (2004-2008), known by participants as “Neighborhood STRENGTH” (STrategies for Reaching Environment and Neighborhood Goals togeTHER). Three questions focus the paper: 1) What was our holistic CBPR approach able to achieve (methods, outcomes and products) that improved our understanding of complex built-environment vulnerability and health outcomes? 2) How were the response/adaptive capacities of partners and residents strengthened? 3) What key lessons did the partnership learn to inform their future work and CBPR practice in general?

### Results summary

We undertook five components: 1) participatory monitoring of pollution; 2) learning about health concerns of residents through listening sessions; 3) undertaking a household vulnerability survey and an asthma prevalence survey for schoolchildren; 4) tackling persistent street trash and illegal dumping strategically; and 5) educating and empowering youth to promote environmental justice. Health data and stress perception data strongly suggest psychosocial stressors dominate. The components built collective capacity among partners to understand and address issues more holistically. We learned important lessons, including: 1) vulnerability theory helps frame issues holistically; 2) having several topic-based projects yielded useful information, but was hard to manage and articulate to the public; 3) access to, and engagement with, the target population was very difficult and would have benefited greatly from having representative residents who were paid at the partners' table to act as community-university ‘connectors’.

## MATERIALS AND METHODS

We obtained IRB approval for the work and informed consent from all research participants. We faced considerable methodological challenges in trying to understand and address complex vulnerability and in integrating five dissimilar components. We combined four methodologies, after Downs (2007): 1) CBPR to build our partnership and carry out community based activities; 2) risk/vulnerability theory to frame and describe complex vulnerability to multiple stressors; 3) a capacity building approach to build the response capacities of partners and the adaptive capacities of residents; and 4) the development of a logic model to manage and elucidate the complex relationships among multiple priority problems, strategies for responding and emerging outcomes.

### Partners

“Neighborhood STRENGTH” comprised four partners: Worcester Youth Center (WYC); Regional Environmental Council (REC), an environmental non-profit; Family Health Center of Worcester, Inc. (FHCW) a community based health center; and Clark University. Partners

were committed to increasing our knowledge about stressors and health outcomes, increasing our capacity to respond, and initiating systemic improvement. We engaged in five main components: 1) monitoring indoor and outdoor pollution; 2) learning about the health needs and concerns of residents through community listening sessions; 3) engaging in collaborative survey research, including a household vulnerability survey and an asthma prevalence survey for schoolchildren; 4) tackling persistent street trash and illegal dumping strategically; and 5) educating and empowering youth to promote environmental justice.

### Study area

Worcester, Massachusetts is the third largest city in New England (2006 population 175,500). In the mid-late 19<sup>th</sup> century, Worcester and the Blackstone River Valley were the birthplace of the U.S. Industrial Revolution, a bustling center of canals and factories. This history however, also means the city suffers from an inherited, persistent pollution burden (e.g. lead in soil, PCBs in pond/lake/river sediments). The Main South and Piedmont neighborhoods of Worcester (Figure 1) are the most densely populated, with the highest rates of minority residents, the lowest income, and the highest crime rates in the city. Residents are vulnerable to many types of ‘environmental’ stress – physical, bio-chemical, social and economic. These factors conspire and can be associated with multiple health consequences at the individual and household scales (Figure 2), requiring a holistic, systems-based perspective. Table 1 compares the census tracts in the study area with city-level indicators. Many people rent dilapidated housing adjacent to abandoned factories and brownfields (abandoned and vacant industrial lots known or suspected to be contaminated), and many move frequently within the same area. Brownfields have become sites for illegal trash dumping, and together with street trash, represent a highly tangible physical and sanitary stressor. Residents interviewed are deeply concerned about this blight yet feel powerless to do anything about it; after sporadic cleanups, it returns. Further, an inland container port, New England's largest, is situated on the edge of the Main South neighborhood, a nexus for trucks and trains 24 hours a day, seven days a week.

### CBPR-Capacity building components

A preliminary conceptualization of complex vulnerability was needed to identify issues and prioritize needs for research and action. We engaged with various community groups, including youth, to draw problem trees of the (perceived) interaction among stressors, causes and effects, creating a preliminary conceptualization of the Main South/Piedmont context (Figure 3). Using secondary data and local knowledge, we determined which components appeared to be of most importance functionally yet were not being adequately addressed by other groups. We chose indicators to characterize each of these primary components, e.g. violent crime rates (violence stressor); asthma rates (air pollution stressor and asthma effect); and average time spent indoors (containment effect). We created an inventory of existing data and information sources (e.g. scientific journals, texts and reports), and mapped local assets including existing projects, to reveal key gaps and opportunities. Five strategic components resulted (Figure 4), striking a delicate research focus/action focus balance. The three research-focused/action-oriented components were: 1) participatory monitoring of indoor and outdoor pollution; 2) learning about the health needs and concerns of residents through community-based listening sessions; and 3) engaging in collaborative survey work, including a household vulnerability survey and an asthma prevalence survey for schoolchildren. The remaining two action-focused/research-informed components were: 4) tackling persistent street trash and illegal dumping strategically; and 5) educating and empowering youth to promote environmental justice.

For each activity, we formed working groups that developed and utilized a broad range of data gathering, decision-making, capacity building, and action tools. Discussed in detail in Results, for the first three research components, we filled priority data gaps with primary data gathering, including participatory outdoor particulate monitoring and household environmental testing;

community-based health listening sessions; a household vulnerability survey; and an asthma prevalence survey for schoolchildren. We deliberately incorporated ways to strengthen partner capacity in these CBPR components. In addition to these information resources, we developed two complimentary groups – trash ‘busting’ and youth empowerment - that were action oriented, targeting systemic change informed by research. A description of the five components, participants and their roles, and outcomes is given in Table 2. We chose two CBPR process criteria to compare them:

- ability to engage with residents – a measure of how easy or difficult it was to engage residents in the activity – high is desirable, low is undesirable;
- conflict burden - the ratio of destructive (i.e. divisive, demoralizing) to constructive conflict among partners – low is desirable, high is undesirable.

We coordinated these components through the Planning and Coordinating Group (PCG), which consisted of two co-PIs, a senior researcher, and a program manager from Clark, representatives from WYC, REC and FHCW, including one community coordinator for the project (at REC), plus four graduate student RAs (three Masters-level per year for four years, and the same Ph.D. student for four years). PCG met once every 3-4 weeks on average throughout the project and was primarily facilitated by Clark. While all four partners were engaged in conceiving the project, PCG did not spend sufficient time in the first year of the project clarifying aims, roles, strategies, specific outcomes, and how the five component projects related to each other. This initial lack of clarity and coherence led to much tension early on, but caused us to adapt and develop a logic model for project management.

## RESULTS

In this section, we describe our five resultant components in detail. Each component is also rated for its ability to engage with residents and the conflict burden among partners.

### 1. “ToxicsWatch” - participatory environmental testing

We created ToxicsWatch to help fill priority gaps in our data inventory and build our capacity. Our problem tree exercises revealed that neighborhood violence and poor physical community conditions acted to “contain” children in their apartments; parents reported preferring to keep their children inside rather than allow them to play in the neighborhood. The group met over a period of three years, on average once a month, to define priority problems, goals and desired outcomes. We were unable to engage residents in technical planning, despite outreach and mobilization efforts. But we did develop two activities that actively engaged residents and stimulated dialogue: 1) household-level environmental testing; 2) outdoor monitoring of particulate matter (PM) on the streets. This component is described in detail in Downs et al. (2008a).

**1.1 Household environmental testing**—Considerable debate and dialogue (often difficult) over an 18-month period resulted in a tenuous consensus on the goals of household testing, which contaminants to test for, and the appropriate tests and technologies to use given budgetary constraints and the goal that residents would continue to test their own homes in collaboration with REC after the project was over. We chose the following eleven tests, and wrote a detailed testing protocol (Adams 2008, Calvache 2008): 1) lead in dust indoors; 2) lead in soil outdoors; 3) lead in paint indoors; 4) lead in drinking water; 5) radon in basement air; 6) PM<sub>2.5</sub> in indoor air; 7) mold spores in indoor/outdoor air; 8) drinking water quality: lead, chlorine, pesticides, nitrates/nitrites, bacteria, pH and hardness; 9) moisture in walls; 10) carbon monoxide sensor status and smoke alarm status; and 11) visual survey. We logged the location of each home using a hand-held Garmin GPS60 (Garmin, Olathe, Kansas).

The community partners were cautious about any tests that could yield ambiguous results or tests that might reveal problems for which we could not provide remediation resources. Phase I consisted of eight homes whose occupants were known to the study team. We used these households to pilot the testing protocol and reporting format. While these households were less representative of our target population, we learned much about testing, analyzing data and sharing the results. Phase II was conducted in six additional households that were more representative of local housing stock.

Pilot data showed several homes with a high lead-poisoning risk, especially for infants; high levels were found in sill and floor dust, and in soil. In Phase II, several changes in protocol occurred. On-the-spot colorimetric water testing was discontinued because of doubts by the community side of ToxicsWatch about the accuracy of results. In addition, mold sampling was done not only indoors (as in the pilot) but outdoors also in order to create an indoor/outdoor ratio of mold that was more informative. One home's data suggested indoor sources of mold (indoor levels/outdoor >30). No other parameters indicated a significant risk. However, some homes did not have functioning smoke detectors or lacked carbon monoxide sensors.

Communicating testing results was integral to our goal of empowering residents. After testing, we interpreted results and tailored reports for each home. Creating reports was very time-consuming. The goal was to present residents with an accurate report that provided adequate resources without being overwhelming. Extensive revisions focused on attractive design and clear, concise wording. Community based partners were critical to this process of translating the results. We held follow-up appointments with residents to discuss results, and ways to reduce potential risks. During the appointment, we gave each resident a customized binder with the results of their household report, and additional resources (such as brochures) for their "pollutants-of-concern". Each binder served as a capacity building tool because it not only presented and explained the results, but also gave suggestions on how to tackle pollution concerns that arose. The comprehensive household reports proved very effective at risk communication. During planning, resident engagement was very low and conflict burden was high, but both became moderate during execution.

**1.2 Outdoor PM Monitoring**—We carried out real-time monitoring of PM 2.5 and PM 10 with a DustScan Scout 3020 aerosol meter (Rupprecht and Patashnick, East Greenbush New York). A series of neighborhood walks was conducted in summer 2006 through autumn 2007, each lasting about two hours. Neighborhood outreach preceded each walk to invite residents to participate. The first part of the walk included a brief summary of the goals of the monitoring, the optical measurement method of the Scout, the importance of respirable PM to health, and questions and comments from residents. We followed a pre-determined route through a cross-section of the neighborhoods and used a hand-held Garmin GPS60 (Garmin, Olathe, Kansas) to track our route, synchronized with the Scout's clock. We gathered PM data as the group of 10-15 people moved along the streets and paused to view and discuss neighborhood blight such as abandoned lots and factories as well as trash piles. After the walks, we had a picnic and viewed the PM data. We downloaded data from the Scout to a laptop computer, and displayed them as a graph of PM level as a function of time. This stimulated dialogue about any spikes, and what the levels imply for health. Residents expressed enjoyment at helping collect data relevant to them and their children. Later, PM data and GPS data were linked manually using synchronous time data, and we produced maps of PM levels as the final output. Resident participation was moderate and conflict burden was low.

To fill data gaps, the academic partner felt it important to gather more PM data, particularly during busy traffic periods, so twelve supplementary walks were undertaken. Data was collected during lunchtime rush hour (about 11:00 am to 1:00 pm) from representative areas of the Main South/Piedmont neighborhood. The timing of walks made it difficult for residents

to participate, and this caused contention with some partners feeling data collection was taking precedence over goals of community participation. Resulting data showed large variability in PM 2.5 and PM 10 levels. Our roughly two-hour PM 2.5 levels often exceeded the NAAQS 24-hour-average standard ( $15 \mu\text{g}/\text{m}^3$ ), suggesting outdoor PM 2.5 may represent a significant risk factor for residents, especially those with pre-existing respiratory conditions. Norris et al. (1999) found that levels of PM 2.5 below the current NAAQS standard resulted in a significant increase in emergency department visits for asthma in children. For supplementary research walks, resident engagement was low, but conflict burden was high.

**Summary:** Home toxics testing was time-consuming up-front because of the need to develop the testing/reporting protocols from scratch, but upon execution proved to be a practical approach with great potential for the empowerment of residents. The most controversial of tests among partners was the mold spore test because of the lack of clarity that surrounds the interpretation of results. The university partner wanted to carry out the test, while the community partners did not want to test homes without being sure how to report the meaning of the results. This is a classic university vs. community conflict of perspectives: researchers want data to fill gaps and downplay uncertainties, while community groups are skeptical of ambiguous results that cannot point to clear action.

The home toxics data did not reveal significant home-based environmental hazards using the indicators chosen, except for high lead levels ( $>1000\text{ppm}$ ) in dust and soil in some homes and lack of adequate carbon monoxide or smoke alarm units in others. But the lack of indoor standards for environmental hazards like mold and particulates make interpretation problematic. The lack of evidence for hazardous homes suggests that the burden of health problems among surveyed residents has much to do with the external climate of physical, social and economic stressors, though a larger sample of homes is needed to make robust claims about relative weight of home vs. external environments.

One of the main outcomes of the household testing was the development and deployment of a detailed testing protocol and reporting format. Though the language of the report needs further simplification to a 6<sup>th</sup>-grade literacy level to be generally applied, the format proved very useful and the activity had high information and capacity-building value for residents and partners alike.

Community PM walks showed the benefit of conducting measurements with community residents and talking about the data generated immediately. This format empowered residents and created interest and enthusiasm for learning more about the issue in a local context. However, PM testing revealed a similar university/community tension as home testing: the community partner was reluctant to undertake any walks without residents, while the university partner was concerned that too few data would be gathered with such a rule. An uneasy compromise was reached that expended reasonable effort to engage residents, and undertook additional walks to gather more data.

In both the household testing and PM walks we resolved conflicts by a process of extended open dialogue during which partners exchanged views with frankness, and spaces were opened for compromise. Specifically, the conflict over mold testing (ambiguous results) was resolved by a special full partners' meeting dedicated to exploring the controversies over the test, during which the university partner presented its case for inclusion based on published literature and a precautionary principal, and concerns were shared. In part the conflicts arose from a lack of clarity about partners' roles and responsibilities at the outset, so we tried to clarify them during conflict resolution and revisit them periodically. Upon reflection, one root cause may have been unexpected turf conflict, specifically in the arena of environmental science, household toxics testing and community engagement. This may explain the protracted nature of the

conflicts; internal turf issues threaten to seriously undermine any project, and call for perseverance and optimism on the part of PIs if they occur, and minimization of the risk during project conception and partnership formation.

## 2. Health Outreach Workgroup

Physicians from Family Health Center reported that obesity, asthma, diabetes, depression, and behavior disorders in children were the most common problems they encountered in the study area. The multi-ethnic composition of their patient base presented a challenge to the physicians trying to help patients manage their chronic conditions. One Latina resident participating in a problem tree exercise provided additional insight into how neighborhood conditions may take precedence over managing their health conditions: “I have asthma, my children have asthma. I know how to deal with it. We can go to the emergency room if we have to. The gunshots... that I can't control.”

This juxtaposition of perspectives signaled the importance of creating the Health Outreach Workgroup (HOW). The mission of HOW was to create a partnership among residents of Piedmont and Main South neighborhoods, community-based organizations and health care providers to improve the health of individuals, families, and our whole community. HOW, made up of representatives from FHCW, REC, and Clark sought to do this in two ways: 1) to better understand and address health concerns and environmental health risks; and 2) to effectively link residents with wellness services. We became interested in developing a Community Health Outreach Worker model, a multi-ethnic version of *promotora* models (Arcury et al. 2008; Lujan et al. 2007).

HOW organized five ‘listening sessions’ from June 2006 to March 2007. The first was a pilot session to practice and refine the dialogue protocol which consisted of questions about participant health concerns, ways participants try to stay healthy, barriers to health care, concerns about how home and work environments impact health, brainstormed ways to improve health and health care, followed by a discussion of community health outreach worker models. The resulting four sessions involved different groups within Family Health Center's patient population: youth, Latino residents, Vietnamese residents, and African immigrant residents. Most sessions were jointly facilitated by STRENGTH and a leader from the group.

**Summary**—The listening session activity was most useful at garnering health views and concerns from different social groups and in fostering partnerships with other community groups engaged in refugee and immigrant health. Such forums proved to be a successful strategy for gathering frank, expressive information that would be less forthcoming in more structured focus group or interview settings. Subtle differences exist, e.g. differences within and between African immigrant and refugee groups regarding health communication, and the stigmatization of certain diseases. Together with more detailed information of health problems (see 3.1 below) health care providers can use the results to improve services. FHCW and Clark also worked to map patterns of patient diseases at the block-group scale to stimulate partner dialogue and learning. Partners differed in their approach to community health outreach, and this caused frustration. The university partner preferred adapting the *promotora* model for community health outreach, while the community health center favored their own “chronic care model”. This difference of opinion underscored the importance of the willingness of CBPR partners to challenge their own conventions and each other's. Resident engagement and conflict burden among partners are both rated moderate. Detailed findings are given in Downs et al. (2009a).



### 3. Survey Research

**3.1 Household vulnerability survey**—We developed a comprehensive household-level questionnaire to assess vulnerability, including existing adaptability. Informed by vulnerability theory (see above) and the multi-stressor models (Figures 2, 3), the questionnaire comprised six sections: demographic data; local knowledge, concerns and resources; time-activity patterns; health information; risk and stress perception; existing capacity and resources. Participation of the community partners allowed for a balanced set of 148 questions about risks, hazards, and health problems, as well as resident strengths, strategies, and resources. Our adaptive sampling strategy combined random sampling, stratified and population-weighted by census tract, with opportunistic sampling. The latter was needed because of considerable access difficulties; it took us 30 months to achieve 80 surveys. Surveys took about 75 minutes to complete. We analyzed the data in SPSS 15.0 and Excel for Windows. Full survey results are given in Downs et al. (2008b).

We gathered data on 254 people in the 80 homes: 132 females and 114 males, (8 ‘missing’); mean age of females 29 years (SD 19, range 0.08-75) and of males 26 (SD 18, range 0.5-78). A third of households have incomes less than US\$10,000/yr, another third \$10,000-\$30,000/yr, and fewer than 10% over \$50,000/yr. Close to 75% of household members have less than \$10,000/person/yr. Most households (94%) have all members able to read and write. About 22% of households have at least one member who does not speak English and 22% at least one who does not read it. About 75% of respondents have at least a high school diploma or GED; of these 20% of respondents graduated from a four-year college.

In terms of neighborhood stressors respondents worry most about: drugs and prostitution, and crime and violence rank either first, second or third most often (each was mentioned by over 50% of the respondents); trash and dirty streets were mentioned by 25%. Pollution and lack of green space are of moderate concern. For sources of stress at home, 19% said financial problems were top, 14% said dealing with children/family, 9% said health concerns, and 9% insecurity issues.

Consistent with the risk/stress perception data, the health data reveals a burden of illness consistent with chronic psychosocial stress, and a statistically significant gender disparity: females on average bear twice the burden of males (Figure 5). The burden warrants comparison with a control population, and the disparity warrants further research with a medical sociology perspective on individual responses to real and perceived illness. The disparity may be because women have a higher stress burden, struggling with multiple roles: mother/primary caretaker of the home, wife, and worker. They may also have lower adaptation capacity than men in some as yet unknown way; both men and women appear to have equally low adaptation capacity from low income, education, and exercise levels, poor nutrition levels, and limited access to community resources. For this activity, resident engagement was moderate and conflict burden was high.

Data from the survey were also combined with secondary data to construct a spatially-explicit household-scale vulnerability index using GIS (Subedi 2008). Approaches in the literature tend to use secondary data, and be constructed at a community scale, with limited resolution (Faber and Krieg 2005, Cutter et al. 2003, Ewart and Suchday 2002). How best to construct such an index and associations between the index value and household disease burden are being explored further.

**3.2 Asthma prevalence in schoolchildren**—Family Health Center was part of a school improvement task group at one of the schools in our study area. This group identified asthma as one of the top three problems that affected students' academic achievement. FHCW brought this to the STRENGTH table. Based on school health records, reported asthma rates in two

neighborhood schools were 11.3% and 14% for the 2006-2007 school year. This is higher than the national pediatric asthma rate of 8.5% (Moorman et al. 2007). Given strong partner and community interest in this topic, one graduate student worked with FHCW to re-evaluate prevalence and learn more about disease characteristics in the study group.

About 1700 surveys were distributed to students at two schools. The survey tool was based on an asthma survey designed for inner city children by Jones, et al (2004). Surveys were written at a 6<sup>th</sup> grade literacy level and were translated into either English, Spanish or Vietnamese. Students gave the surveys to their parents or guardian to fill out: 629 (37%) of surveys were returned and 569 used for analysis. Children were put into three groups: 1) “Self-ID”: children whose parents said they have asthma; 2) “Symptomatic”: parents either answered “no” to the self-ID question or left that question blank, but answered positively to any other symptom question except indicating “rarely” in the question about exercise-induced symptoms; and 3) Non-symptomatic: no asthma or symptoms were reported.

Of the 569 surveys used for analysis, 27% (153) were ‘asymptomatic’, 20% (113) self-identified (self-ID) with asthma and 53% (303) were ‘symptomatic’. Results suggest rates based on physician diagnosis may considerably underestimate prevalence and that better identification/diagnosis is needed. Many children in the self-ID group had severe symptoms that impacted their daily life (missed school, ER visits) compared with the symptomatic group. (Wysokenski 2007). Symptomatic and self-ID students enrolled in the school-based health center were evaluated by nurse practitioners using further questioning and testing of peak respiratory flow. If a student was diagnosed with asthma, an asthma action plan was developed. Results were shared with the school task group, and used to recommend improvements in asthma screening, diagnosis and management, emphasizing school-family-community partnerships. Resident engagement was moderate and conflict burden was very low.

**Summary:** Throughout the vulnerability survey, the university partner struggled to articulate the need (and justify the considerable effort expended) for systematically collecting household data to document what many claimed was already known anecdotally. In hindsight, if a technique developed early in the partnership becomes problematic or inefficient, it is an opportunity to reevaluate (and possibly change) it while still maintaining its most important analytical characteristics. In striking a research/action balance, one detailed survey tool, while academically appealing, may be less effective than several shorter ones. Shorter surveys can be more quickly analyzed and results presented to the community. Further surveys can then be tailored to evolving knowledge with community input. Whether one long or several short surveys are employed, the demand on resources can become large, and their objective(s) must be justifiable.

#### 4. Main South Trash Action Group

In our initial problems trees, and subsequent interviews, surveys, class projects, focus groups, and listening sessions, trash was a clear priority. Aside from REC's yearly *Earth Day* clean up, no previous efforts proved sustainable in Main South or Piedmont. For this reason, STRENGTH convened the Main South Trash Action Group. We designed the first meeting to be highly interactive: after an icebreaker, we reviewed and ranked issues and potential solutions that had been previously identified. A dozen residents attended the first meeting and agreed that the main problem was illegal dumping and street litter in the neighborhood. In discussing the issue, they identified a number of barriers for residents to dispose of bulk items legally, such as fees, not having a checking account, and lack of means to deliver items to the waste drop-off site. The group held strategic planning meetings once a month for four months in 2006/07 to organize two bulk-waste pick-up days, three months apart. To date the group has created a protocol for community-led bulk waste pick up days and carried out two bulk waste

collections with the support of the City of Worcester, the city's trash hauler, and over 20 volunteers. In September 2007, more than 250 bulk items were collected from 42 participating households. Money collected from the pick-ups, plus a small grant, has purchased trash barrels for Main Street to be maintained by local businesses.

**Summary**—Trash clean-up was the most successful of our five projects at producing genuine resident engagement and ownership. It benefited from the university partner's assistance with decision-making models, and the provision of previously gathered research data (including GIS maps) on trash hotspots. Resident engagement was high due to pressing and very tangible nature of the trash problem and conflict burden among partners was very low.

## 5. Youth “A” (for Action) Team

Youth participation was critical to all phases of STRENGTH, including conceptualizing neighborhood vulnerability (Figure 3). We created an environmental health-focused youth group at the Worcester Youth Center, and used the Urban Community Action Planning for Teens (UCAPT) curriculum. UCAPT is a participatory, experiential youth program designed to engage low-income, urban adolescents in neighborhood problem-solving and planning. It helps adolescents find the voice to define themselves, their needs, and the neighborhood problems that most trouble them (Ross 2002; Ross and Coleman, 2000). Over a three year period, 30 young people participated and received stipends from STRENGTH. The group was facilitated by a different graduate student each year.

The youth analyzed the strengths and problems of their neighborhood. Transect walks allowed the team to make comparative observations in their own neighborhood and a more affluent one. We gave the youth disposable cameras and GPS units to map assets like parks and liabilities like trash. With the help of Clark students, they created maps with GIS and used their visual data to discuss the nature of problems, causes and possible solutions. They used a pair-wise ranking matrix to rank problems against each other. The top three problems they identified were racism, pollution/trash, and a lack of activities for youth. Of the three problems, renovating an old neighborhood basketball court was chosen as the achievable goal. Through two community-based fundraisers organized by the youth and grants written by adults, with input from youth, the group raised money and created much-needed recreational space.

**Summary**—Children and teens are among those most vulnerable to stressors, suffering health and development consequences. Yet they are often excluded from action research that targets them (Chao and Long 2004). Authentic and meaningful involvement by youth happens when youth play a role in decision making, receive stipends, and when research is flexible and suits youth interests and schedules. STRENGTH's “A-Team” project was successful at creating such a dynamic, and though not formally evaluated, the 30 teens who participated (10 a year for three years) became energized and empowered to design activities and engage with issues of importance to them, including the creation of recreational space. Resident engagement was high and conflict burden was moderate.

## DISCUSSION

### Approach

The vulnerability framework is better than a traditional risk assessment approach at capturing exposure to multiple environmental stressors (Figure 2), and socio-economic adaptation capacity. The project was able to use a practical holistic approach to produce wide-ranging information, capacity building, and action outcomes (Table 2). However, attention to multiple problems tends to cause efforts to become diffused, uncoordinated, tense among partners, and

difficult to articulate to the wider public, including policy makers. Much energy is required by partners to keep the project manageable, enjoyable and productive.

It is appropriate to reflect on our experience of the five components, their findings and the overall project in order to re-inform our understanding of vulnerability at three scales: individual, household and neighborhood/community. Taking the aspect of exposures to stressors first, findings from the household survey validated the conceptual model (Figure 2) and problem tree model (Figure 3), while toxics testing filled-in specific data gaps to add contextual information. Missing from the initial models was the aspect of adaptive/coping capacity; all five components contributed to a greater understanding of existing capacity, and made progress towards strengthening the same. The household survey in particular was designed based on the stressor models and vulnerability theory, and its findings provided a rich contextual picture of life, stress, coping and health burdens.

Power imbalances are inevitable in CBPR work and need to be mitigated. In our case, university members of the core project team out-numbered the other partners at the monthly coordinating meetings, having an average of six representatives (including four graduate students), compared to two for REC, and one each for WYC and FHCW. This created a persistent imbalance, and may have contributed to tensions between the university and community members of the project team. CBPR projects face barriers inherent in their nature: participants have unequal power, and significant cultural, racial/ethnic, linguistic and socioeconomic differences exist among them (Srinivasan and Collman 2005). Central to overcoming these barriers is fostering mutual respect and making sure research focuses on community needs and concerns. Our survey research generated considerable tensions among the partners regarding purpose, effort, design, tools, data collection, analysis, and interpretation. Activities responding to clear community concerns were much easier to conduct as a partnership. For example, the community and FHCW were eager to work on asthma and drew on Clark's research capacity to do so. Likewise, since trash is a chronic, highly visible problem in these neighborhoods, we were able to engage residents very effectively and help build their capacity to solve this problem.

### Comparison with other studies

How is STRENGTH similar and/or different to other CBPR work? Shephard et al. (2002) describe the work of West Harlem Environmental Action (WE ACT), an environmental justice organization, a health promotion partner, an academic partner, and the NIEHS Center for Environmental Health. Their CBPR approach undertook air monitoring, asthma research, and training courses for community leaders, and it influenced policies. While STRENGTH deliberately avoided a focus on any one topic of concern in its effort to foster holistic approaches to environmental health, it was only weakly to moderately successful at engaging the target community in its activities, and the success varied considerably by activity, from very low to high (Table 2). This was a persistent conflict issue and bone of contention among two of the four partners during the project: one community partner felt that the university partner created obstacles to engagement by pursuing data gathering activities not conducive to resident participation, while the university partner, on the defensive, likewise did not think the community partner was doing enough to engage residents.

The social psychologist, Kurt Lewin, coined the term “action research” in the 1940s, the marriage of academic research and community interests to affect social change (Kangsen Scammell 2004). Within the context of university-community partnerships, however, the “action” part is often viewed as belonging to the community advocacy groups, while the “research” is the academics' territory. CBPR researchers in academia have to do a delicate parsing between the two, making sure their research informs and promotes action for social change without trespassing on the turf of activist and advocacy groups. Lewin recognized the

importance of “intergroup relations” in the work, as well as the interactions among academic researchers, the subjects of research, and other groups. Any real or perceived competition or turf squabbles among partners undermines the goals of the work, and hinders the building of trust and cooperation so vital to success. STRENGTH, unfortunately, while it achieved much from its various activities described above, did suffer from an undercurrent of mistrust and unspoken issues of territoriality among some of its partners. Intergroup tensions emerged, eased then re-emerged.

Roots of CBPR lie with the vision of creating alternative research forms as ways to effect social change, so researchers must strive to respond to community concerns and build genuine and empowering partnerships. The term “genuine” here is similar to the use of the term “authentic” elsewhere in the literature (Agyeman 2005, Chao and Long 2004), and refers to the degree to which a project reflects not only community concerns, which STRENGTH did do quite well, but also how well it literally ‘wears the face of the community’, by having low income marginalized groups employed in key positions on the project team, something the project failed to achieve. The experience of Alternatives for Community and Environment (ACE) is relevant here. Working in Boston's Roxbury district since 1994, ACE is dedicated to the eradication of environmental racism and classism, and to social justice, and focuses on issues of youth, air pollution, transportation, and environmental health (Agyeman 2005). A multicultural workforce that reflects its target population wins local credibility. The in-house blending of research rigor, community building, and policy advocacy are reasons for its impact and authenticity, allowing CBPR-type challenges and difficult group interactions to be internalized and mitigated, something most university-community partnerships, like STRENGTH, cannot do. ACE work also shows that success in community organizing and CBPR has more to do with the messenger than the message: CBPR projects need a face that is credible to environmental justice communities.

CBPR work to change a regional regulation (Rule 1402) governing allowable lifetime risk levels and toxic emissions from stationary sources was undertaken by the Southern California Environmental Justice Collaborative (Petersen et al. 2006). Success depended on strong members who worked well together, a clear goal with high relevance, legitimacy in the eyes of local people, ample funding, a favorable political climate, and positive media attention. STRENGTH's holistic goal was not easily articulated, and our partners struggled to work in concert.

Schell et al. (2005) describe a CBPR approach to understanding health disparities and toxicant exposures of Akwesasne Mohawk young adults in upstate New York. Hiring community members as key personnel, bringing local expertise to bear on research design and implementation, and development of a community education and outreach program all helped build a more equitable partnership. One guiding principle is the equitable distribution of project benefits, and it is one that STRENGTH worked hard to achieve; partners were able to build significant capacities both individually and collectively. Corburn (2005) writes of CBPR lessons learned in Brooklyn's Greenpoint/Williamsburg district, concluding that what he terms “street science” can only be integrated with academic science provided the participatory process blends flexibility with agreed-upon rules of cooperation, and professionals work to understand and respect local “street” rules and norms. While the burden to understand local context clearly lies with university researchers, community partners share the responsibility for respectful and constructive dialogue.

### **Wider impact and sustainability**

The work described is having sustainable impact. Our survey knowledge is informing the newly awarded National Children's Study-Worcester County, a University of Massachusetts Medical School-Clark University collaboration. FHCW is improving its services in light of the new

information about patient needs and concerns. Youth continue to use their experience to become more proactive champions of their local environment. REC plans to adopt a healthy-homes approach to toxics' testing and focus its efforts on community mobilization. The trash group continues to tackle the bulk waste issue. And STRENGTH partners continue to participate in the Worcester Lead Action Collaborative, a multi-stakeholder group our project helped start in 2005 to target the priority of childhood lead poisoning prevention. The Collaborative received a large grant from the US Department of Housing and Urban Development in 2007 for strategic lead abatement that targets vulnerable residents. Our wider goal of community empowerment is also being met by the creation of an online Community Information and Training Resource (CITR) – see *Neighborhood STRENGTH.org* – to serve the interests of residents, community groups, public agencies and researchers (Table 2).

## CONCLUSIONS

In Main South/Piedmont, low income, multi-ethnic communities are exposed to cumulative, chronic built-environment stressors and have limited capacity to respond, magnifying their vulnerability to adverse health outcomes. Such settings are arguably the norm and the most challenging contexts for CBPR. What was CBPR able to achieve that improves our understanding? Health data and stress perception data strongly suggest psychosocial stressors dominate; the burden of chronic, stress-related illness appears considerable, especially among females. Listening to the voices of different social groups informed the science, as did residents' participation in testing the outdoor and home environments they inhabit. How were response/adaptive capacities of partners and residents strengthened? The components built collective capacity among partners to understand and address issues more holistically; we strengthened our knowledge, and organizational and functional capacities. But this often happened through heated discussion rather than an intentional, dialogic learning process; our assessment of “conflict burden”, highly variable among CBPR activities, helps capture the nature of discord.

What key lessons inform future work, and CBPR practice? The main ones were:

### Theory and practice

- Vulnerability helps us frame issues holistically, interpret health burdens and disparities, but how we organize partnerships to address the holism matters greatly; collective capacity building helps reduce vulnerability and increase sustainability, but is limited by the effectiveness of the partnership and the wider social network it develops.
- While a desirable balance can be struck between action-oriented research and research-informed action, it is difficult to accomplish, and unless all CBPR partners are mindful of balancing, tensions persist and conflict burden is moderate to high.
- Beyond partner capacity building, community building (e.g. local leadership development) must be central because, when allied with problem solving-based activities, resultant work is more authentic and more likely to stimulate systemic, sustainable social change.

### Design and process

- Clarify and agree-upon aims, roles, strategies, and specific outcomes early on with partners. Spend considerable time on visioning up-front then review regularly. Be willing to change strategies if needed, be transparent and discuss frequently the different interests partners bring to the table which influences perspectives.
- Access to, and engagement with, the target population was very difficult and would have benefited greatly from having representative residents who were paid at the partners' table to act as community-university ‘connectors’.

- Partners must cultivate positive, team-building attitudes and be willing to challenge their own norms, venture outside their own comfort zones; the place of CBPR success lies beyond their initial territories and experiences; avoiding internal turf conflicts is a priority.
- Avoid spending too much energy on primary data gathering activities so as to be able to invest more energy in relationship-building; strategic blending of primary and secondary data will be more efficient.

### Following-on

- Activities that are not ready-to-go, that start from scratch like ours, may tend to compete for resources, and partner accord may be harder to reach. In follow-on work, we are creating an *informal social network* of partners with stakes in *compatible ready-to-go activities*, allocating resources to each one equitably, and linking them by funding the development of valuable new human ‘connectors’ from the target population.

Communities, especially those who are marginalized, have a legitimate concern about how CBPR funding is spent, and allocated. As long as there is a perceived or real barrier between academic research and community action, such criticism will continue to resonate. The real challenge of CBPR is to be authentic and effective at combining action-oriented research with research-informed action, a function of trust and communication: residents-at-risk must be full partners with health scientists, health care providers, public health agencies, educators and environmental protection agencies. Holistic CBPR approaches that venture beyond single hot-button issues are highly complex both politically and technically. However, to adequately comprehend and fix chronically stressed built environments – the fastest growing human habitat on the planet – the urgency for their development and deployment continues to grow.

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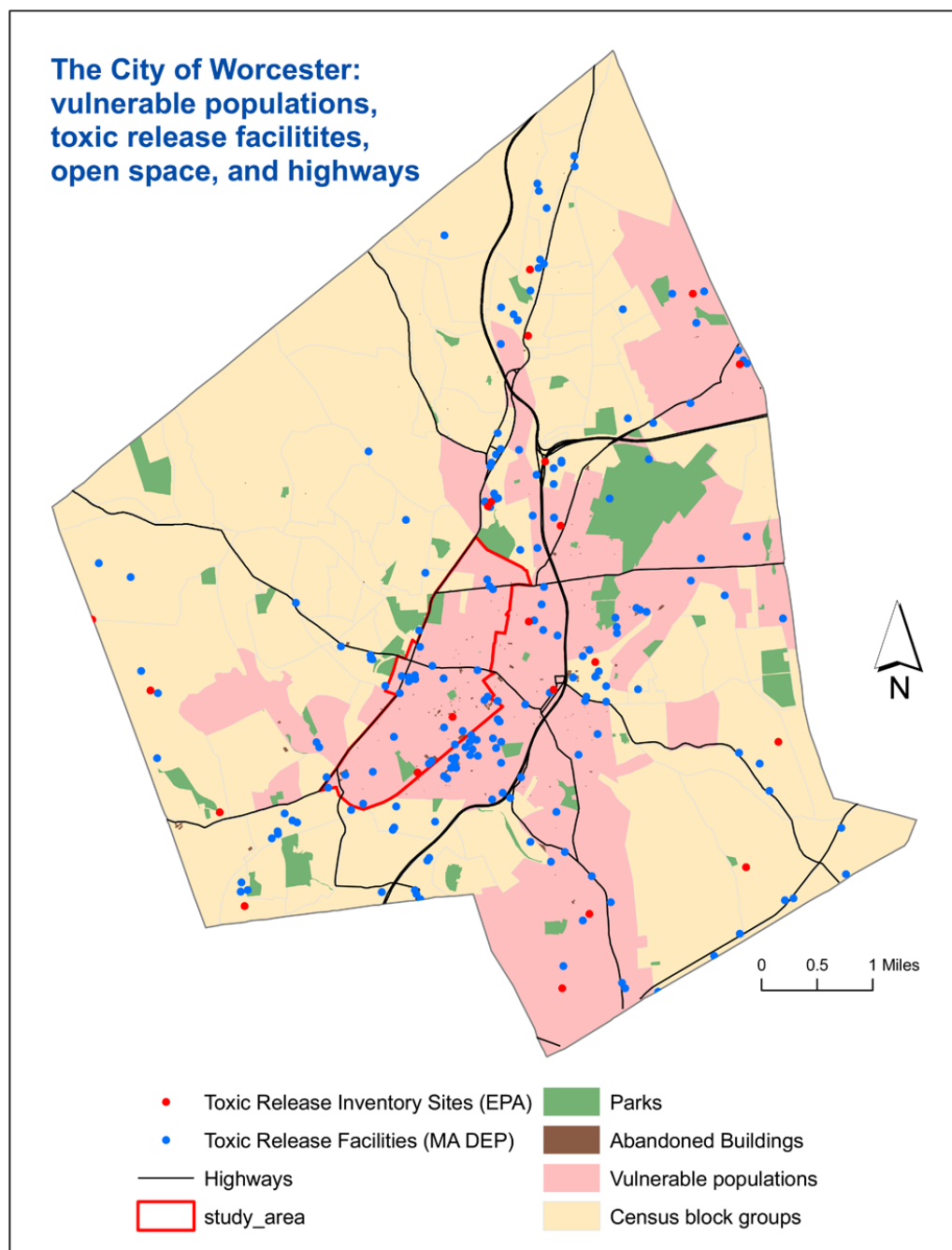
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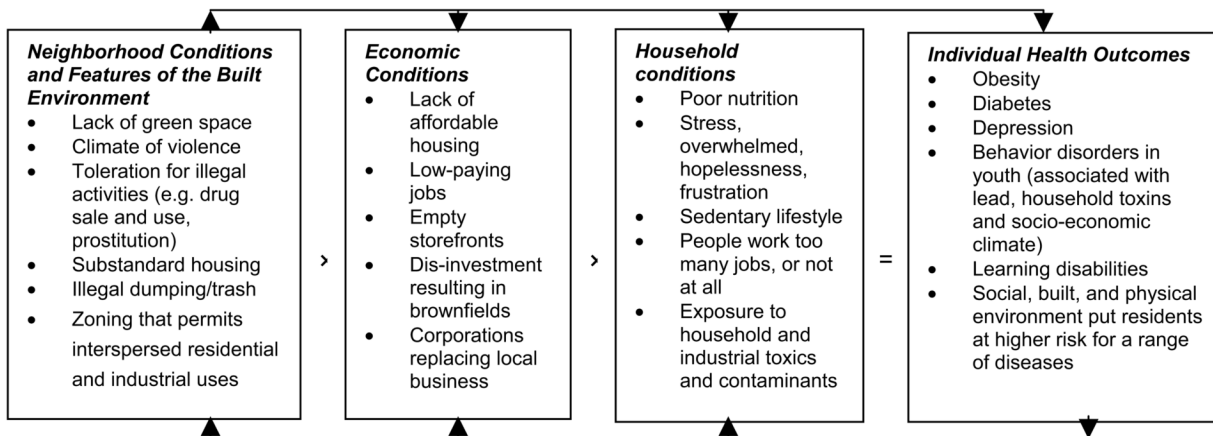


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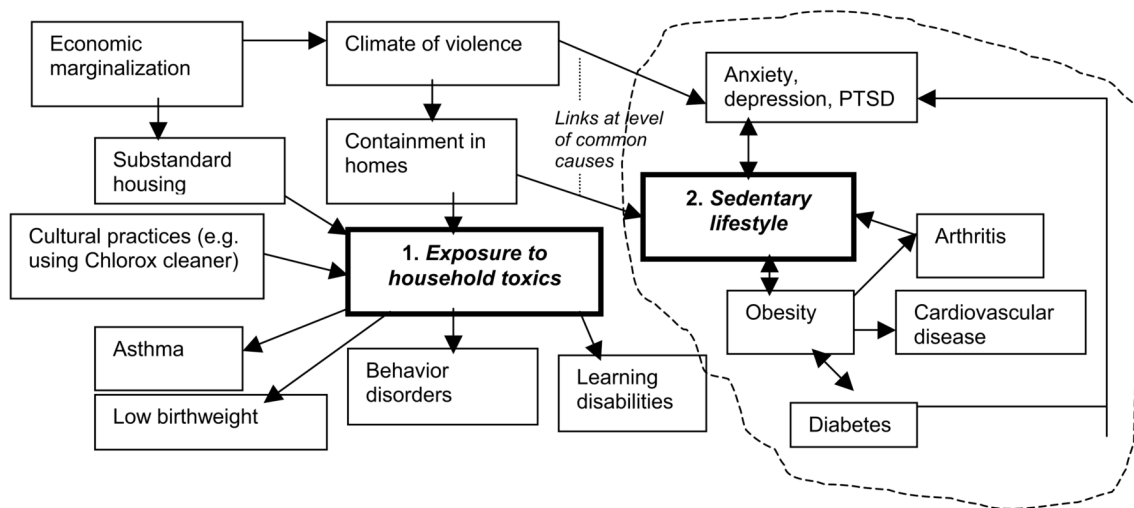


**Figure 1. Study area in Worcester City**

Shows lack of green-space, toxics release inventory (TRI) sites (2006 data), and highways. Vulnerable groups are designated as “environmental justice populations” according to US Census 2000 socio-economic data (Census 2000). Map prepared by Yelena Ogneva-Himmelberger.

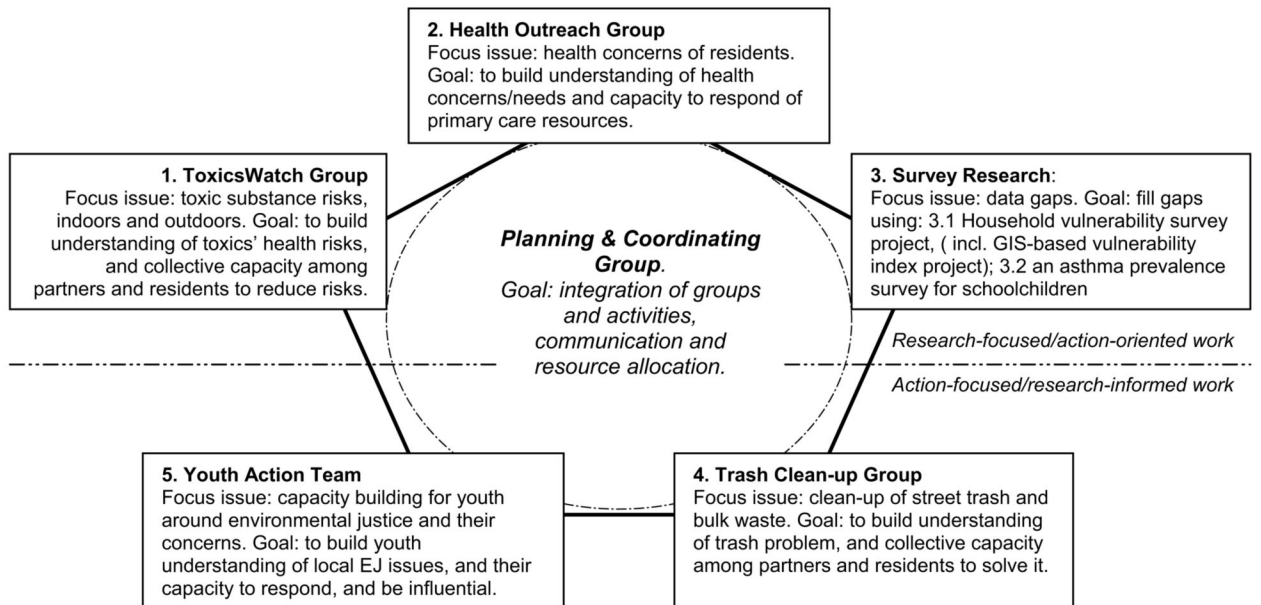


**Figure 2.** Conceptual model of multi-stressor exposure at the individual and household scales.



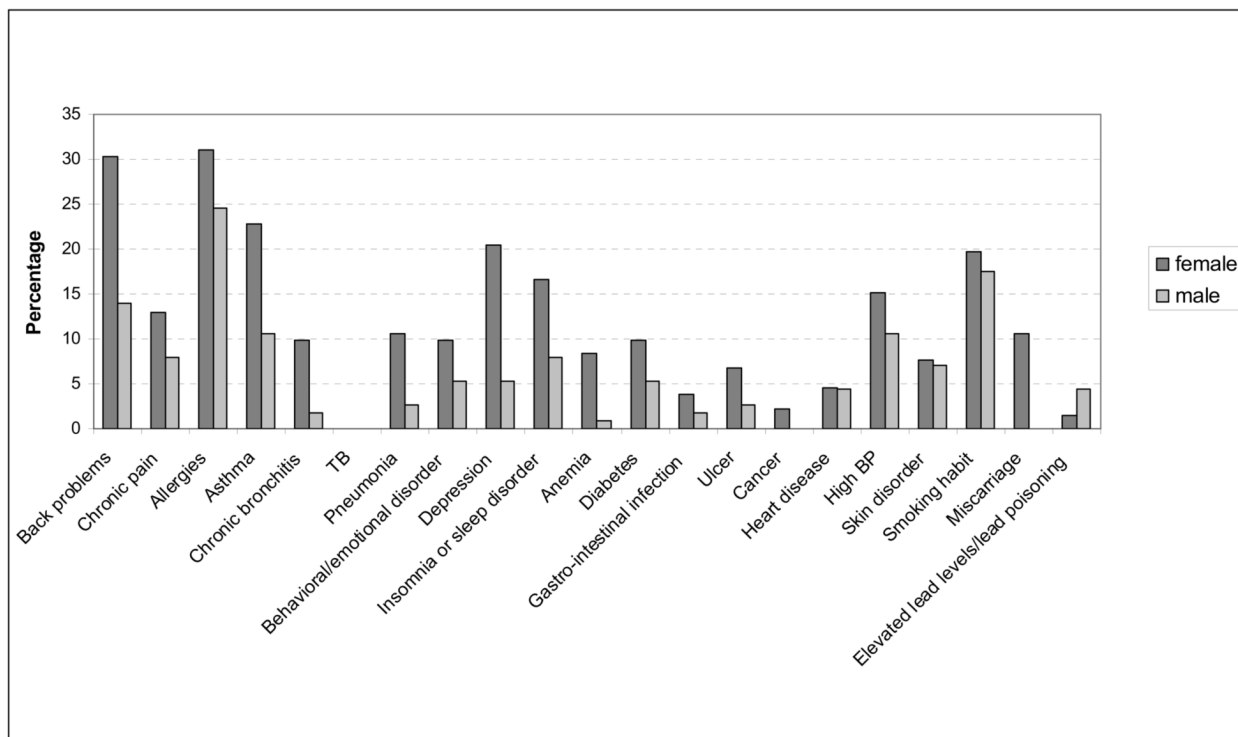
**Figure 3. Problem tree model of multi-stressor exposure perceived by youth**

The model shows drivers of two problems – exposure to toxics and sedentary lifestyle - in the upper portion, and health outcomes in the lower portion. The problems and the drivers are the result of dialogue with locals (in this case, teens from the Youth Center), while the outcomes are suggested by the literature. (Downs 2007, by permission of Blackwell Publishing)



**Figure 4. Holistic topic-based CBPR approach**

The five components and their focus topics represent a prioritized, manageable set of issues related to complex vulnerability. The approach strikes a tricky balance between research-focused/action-oriented and action-focused/research-informed work.



**Figure 5. Gender distribution of 21 health problems by percentage**

A gender disparity was revealed: on average females have twice the disease burden ( $M = 2.545$ ,  $SE = 0.2713$ ,  $Var = 9.715$ ,  $n = 132$ ), of males ( $M = 1.351$ ,  $SE = 0.2713$ ,  $Var = 3.628$ ,  $n = 114$ ,  $t(221) = -3.67$ ,  $p < 0.01$ ). (See Downs et al. 2009b for more detail).

Table 1

**Demographic profile of study site**

Main South/Piedmont census tracts included in the study area - 7313, 7314, 7315 - have much larger proportions of people of color (70, 75 and 60% respectively), and people living below the poverty line (40, 38, 34% respectively), compared to the city as a whole (30% people of color, and 18% in poverty). Main South (7313) and Main Middle/Piedmont (7314) are 44.3% and 47.7% Latino, respectively, compared to a city proportion of 15.0%. Main South has population density 12,640/sq. mile, compared with 4,600/sq. mile for the city as a whole. (Data from Census 2000)

	City of Worcester	Census Tract 7313 (Main South)	Census Tract 7314 (Main Middle/Piedmont)	Census Tract 7315 (Elm Park/Piedmont)	Census Tract 7316 (Elm Park/Piedmont)
Population	172,648	3679	4516	4801	6791
Race/ethnicity - % White alone	<b>70.1</b>	<b>30.2</b>	<b>25.2</b>	<b>39.6</b>	<b>70</b>
% Black alone	6.4	7.6	14.3	12.7	6.8
% Asian alone	4.5	11.5	7.8	5.1	5.4
% Latino	15	44.3	47.7	39.6	12.4
Place of Birth - % Native	85.4	80.8	74.4	69.8	79.1
% Puerto Rican	5.5	19.8	18.9	14.5	3.8
% Foreign born	14.5	19.1	25.5	30.1	20.8
Median household income	35,623	23,029	17,754	19,599	22,188
% below poverty level	<b>17.9</b>	<b>40.4</b>	<b>38.1</b>	<b>33.6</b>	<b>35.0</b>
100% count of housing units	70,723	1,380	1,831	2,078	2,782
Median year housing built	1946	Before 1940	Before 1940	1942	Before 1940
Occupancy status - % vacant	5.2	10.1	12.1	10.0	6.7
Tenure - % owner-occupied	43.3	13.6	12.9	12.1	11.0
Median Gross rent as % of	25.1	29.8	28.1	27.2	31.2

	City of Worcester	Census Tract 7313 (Main South)	Census Tract 7314 (Main Middle/ Piedmont)	Census Tract 7315 (Piedmont)	Census Tract 7316 (Elm Park/ Piedmont)
Household income					
Population density (no./sq. mile)	4,600	12,640	16,129	20,517	14,480



Table 2

**Description of five STRENGTH components**

Also shows rating for ability to engage with residents, and conflict burden among partners (the ratio of destructive to constructive conflict). All components contribute to the online community information and training resource (CITR).

"Group name" or component project – topic focus	Activities	Participants - Roles	Outcomes	ability to engage residents	conflict* burden
<i>Research-focused, action-oriented components</i>					
1) "Toxics-Watch" – toxic substance risks	1.1) household testing	REC – community outreach and education, mobilization, selection of tests and protocol design, testing and follow-up. Clark - selection of tests and protocol design, testing and follow-up. Residents – participation in testing of their homes.	Database of results, protocol, training of participants, information for CITR, reported in this journal article.	planning – very low execution - moderate	planning – high execution - moderate
	1.2) PM monitoring walks a. Community walks Supplementary walks	REC – community outreach and education, mobilization, logistics Clark – equipment, maps, education 6 Residents - monitoring, local knowledge, results dialogue	Database of results, protocol, training of participants, information for CITR, reported in this journal article.	a. moderate b. low	a. low b. high
2) "Health Outreach Working Group" – health concerns and needs	listening sessions with youth, and Latino, Vietnamese, African immigrant residents	FHCW – community outreach and mobilization, logistics. REC – helping run sessions and log information Clark – helping run sessions and log information	Information from youth, and Latino, Vietnamese, African immigrant residents, report, information for CITR.	moderate	moderate
3) Surveys – vulnerability information 3.1) Household survey 3.2) Asthma prevalence in schoolchildren	3.1) gather data from a random sample of residents 3.2) gather data from a random sample of children	Clark – survey design, outreach, data gathering, processing REC/FHCW/WYC – feedback on results FHCW – co-design and execution Clark - co-design and execution	Database of 80 homes, journal article manuscript, information for CITR. 3 MA theses. Report, 1 MA thesis, information for CITR.	moderate	high  very low
<i>Action-focused, research-informed components</i>					
4) "Trash clean-up" – street trash and illegal dumping	bulk waste clean-up days	6 Residents – planning of activity, execution REC - community outreach and mobilization, logistics, facilitation. Clark – outreach support	Training to plan activities, two bulk-waste clean-up days, information for CITR.	high	very low
5) "Youth 'A' Team" – capacity building	basketball court rehab., neighborhood profiling, relevance of climate-change issue locally	8 Teens – design and execution of activities WYC – host of activities Clark – facilitation of activities	Information for CITR, 2 MA theses on youth empowerment.	high	moderate

Key: REC – Regional Environmental Council; FHCW – Family Health Center of Worcester; WYC – Worcester Youth Center; Clark – Clark University; CITR – community information and training resource (online): see [NeighborhoodSTRENGTH.org](http://NeighborhoodSTRENGTH.org)

\* ratio of destructive to constructive conflict: low is desirable; high is undesirable