Outline of EPA Asthma Panel presentation 5/26/04

Marian Feinberg and Carlos Alicea
South Bronx Clean Air Coalition
sbcac@earthlink.net

What is the relationship between asthma science and environmental justice?

MUCH OF THE ENVIRONMENTAL JUSTICE WORK IN THE SOUTH BRONX HAS REVOLVED AROUND ASTHMA. The asthma hospitalization rates in the South Bronx are about 10 times the national average. The South Bronx is surrounded by diesel-truck filled highways, is home to dozens of waste transfer stations, four power generators, over 60% of the sewage sludge processing of NYC, and numerous other polluting point sources.

ALBERT EINSTEIN: PROBLEMS CANNOT BE SOLVED WITH THE SAME THEORY BY WHICH THE PROBLEMS WERE CREATED.

ENVIRONMENTAL JUSTICE DEMANDS A NEW PERSPECTIVE ON SCIENCE—WHAT IS IT, WHO MAKES IT, WHO VALIDATES IT, WHO CONTROLS IT, WHO DISSEMINATES IT. What makes some observation and investigation "anecdotal evidence," and other observation and investigation "science?" What is the relationship of science and the precautionary principle? Is there objective science?

THE EXPERIENCE OF THE SOUTH BRONX CLEAN AIR COALITION IN MAKING AND USING ASTHMA SCIENCE:

---CASE OF THE BFI-Bronx Lebanon REGIONAL MEDICAL WASTE INCINERATOR—COMMUNITY OBERVATIONS AND PHYSICIAN DATA ANALYSIS CREATED AN EPIPDEMIOLOGY WHICH SUPPORTED THE FIGHT TO CLOSE THE INCINERATOR. AT THE POINT WHERE THERE WAS TREMENDOUS MOMENTUM TO CLOSE IT, OTHER SCIENTISTS PUSHED FOR A THREE-YEAR STUDY ON THE EFFECTS OF THE INCINERATOR WHICH WOULD HAVE NECESSITATED KEEPING IT OPEN TO COMPLETE THE WORK.

---CASE OF NYOFCO—COMMUNITY NETWORKS OF COMMUNICATION AND TRUST DISCOVER A NEW WIDESPREAD SYMPTOMOTOLOGY AND PINPOINT ITS SOURCE. GOVERNMENT FAILS TO TEST FOR CRITICAL ASTHMAGENIC SUBSTANCES. ENGINEER HIRED BY COMMUNITY BOARD FAILS TO BE ACCOUNTABLE TO COMMUNITY. ACADEMIC RESEARCHERS APPEAR AND DISAPPEAR WHEN FUNDING DOESN'T COME THROUGH. THE FACILITY IS STILL OPEN, AND PEOPLE ARE STILL SICK. THE PEOPLE HAVE DONE THEIR OWN SCIENCE—THEY KNOW THEY FEEL SICK, AND ARE IN RESPIRATORY DISTRESS, PRINCIPALS KNOW THEY MUST PULL THEIR CHILDREN IN FROM RECESS WHEN THE "SMELL COMES", ***IN THE ABSENCE OF HARD SCIENTIFIC DATA THAT PINPOINTS SINGLE SUBSTANCE(S) CAUSING RESPIRATORY SCYMPTOMS NEAR A GIVEN FACILITY, WHY IS COMMUNITY INVESTIGATION AND OBSERVATION NOT ENOUGH TO INVOKE THE PRECAUTIONARY PRINCIPLE? CAN TRADITIONAL SCIENCE (WAITNG FOR MAGIC NUMBERS) BE HOLDING BACK HEALTH PROTECTIVE GOVERNMENT ACTION?***

---CURRENT PARTNERSHIPS

1. MONTEFIORE MEDICAL CENTER/ALBERT EINSTEIN COLLEGE OF MEDICINE:
    a. THIS PARTNERSHIP EMERGED FROM A WORKING RELATIONSHIP WITH THE DEPARTMENT OF SOCIAL MEDICINE THAT PROCEEDED FUNDING. THE PRIOR RELATIONSHIP, AND THE OPENESS OF PI AND HIS EXPERIENCE WITH AND COMMITMENT TO WORKING WITH COMMUNITY GROUPS HAS MADE THIS PARTNERSHIP RUN WELL.
    b. *GIS-BASED ASTHMA RESEARCH CORRELATING CENSUS-TRACT ASTHMA HOSPITALIZATION DATA WITH PROXIMITY TO HIGHWAYS AND POINT SOURCES.* THIS RESEARCH BASED ON A COMMUNITY QUESTION RE: DO ASTHMA OUTCOMES WITHIN THE COMMUNITY VARY WITH PROXIMATE EXPOSURES TO AIR POLLUTION SOURCES, MOBILE AND POINT? ARE THERE WORST CASE SENARIO MICRO-ENVIRONMENTS WITHIN THE COMMUNITY?
    c. SBCAC WAS NOT ABLE TO TAKE FULL ADVANTAGE OF PARTNERSHIP OPPORTUNITIES TO DEVELOP ITS GIS CAPACITY. RELATIVE TO ACADEMIC PARTNERS, COMMUNITY

GROUPS ARE UNDER-RESOURCED AND DEALING WITH COMMUNITY SITUATIONS AND DEMANDS THAT ARE FREQUENTLY IN CRISIS MODE. WHEN CAPACITY-BUILDING IS PART OF THE PARTNERSHIP, EFFORTS MUST BE MADE BY COMMUNITY GROUPS TO PROTECT THE STAFF DEVELOPMENT TIME AND FOR FUNDERS AND ACADEMIC PARTNERS TO ASSURE RESOURCES SUFFICIENT FOR THESE TASKS AS WELL AS OTHER COMMUNITY RESPONSIBILITIES.

2. COLUMBIA UNIVERSITY SCHOOL OF PUBLIC HEALTH—CO-PARTNERS WITH WEST HARLEM ENVIRONMENTAL ACTION, ANOTHER COMMUNITY ORGANIZATION.
    a. *RESEARCH MEASURING HIGH SCHOOL STUDENT EXPOSURES TO DIESEL RELATED POLLUTION AT THEIR SCHOOLS AND IN HOME AND OUTDOOR ENVIRONMENTS.* THIS IS A COMPLEX PROJECT INVOLVING AIR MONITORS AT SCHOOLS, PERSONAL MONITORING, GENERAL AND SYMPTOM SURVEYS.
    b. PROJECT WAS NOT PRECEEDED BY COMMON DISCUSSIONS AND UNDERSTANDINGS OF CBPR AND RELATIONSHIPS BETWEEN THE ENTITIES.
        i. THIS HAS MEANT HARD WORK TO HAVE THOSE DISCUSSIONS AND BRIDGE THE GAPS.
        ii. PARTICULARLY AMONG THE MORE TECHNICALLY ORIENTED MEMBERS OF THE TEAM, IT HAS BEEN DIFFICULT TO COMMUNICATE AND GET RESPECT FOR THE OPINIONS AND INTERVENTIONS OF COMMUNITY REPRESENTATIVES.
        iii. ISSUES HAVE ARISEN ABOUT RELEASING PRIOR DATA TO THE COMMUNITY DURING THE STUDY. WHAT IFORMATION IS APPROPRIATE TO RELEASE IN A STUDY OF SERVERAL YEARS DURATION? TO WHOM? WHEN? WHO DECIDES? SCIENTISTS WANT TO RETAIN DATA SEPRE-PUBLICATION. COMMUNITY GROUPS WANT TO RELEASE DATA TO INCREASE COMMUNITY KNOWLEDGE AND MOBILIZATION.

OTHER ISSUES

WHAT IS SCIENTIFIC ROLE OF COMMUNITY-BASED EJ ORGANIZATIONS?

1. SERVE AS INTERMEDIARY BETWEEN ACADEMIA AND GRASSROOTS COMMUNITY
    a. Raising issues, observations, deductions of the community to academic scientists.
    b. Championing the community perspective with partners
    c. Translating research data into meaningful and understandable formats for the community
2. EVALUATE GOVERNMENT AND INDUSTRY SCIENCE FOR COMMUNITY
    a. Publicize and mobilize for democratic input into science behind EISs, facility engineering, permits and planning
    b. Advantage in SBCAC of staff and volunteers with academic science training
3. ENCOURAGE "SCIENCE FOR THE PEOPLE"
    a. Work with community members, especially youth, to increase skills in mainstream and community-driven science, analytical and critical thinking
    b. Work to increase confidence of community members in their own observations, analysis and experience and encourage further development of analyses.
    c. Work for an end to hierarchies of knowledge
        i. If we are to truly have government of, for and by the PEOPLE, then the input of the people must be valued
        ii. Why must community analysis always be mediated and validated by hard-to-access, expensive, repetitious, and time-consuming academic science for government to act in the face of continued suffering?
        iii. Mainstream science should be valued for all the new things about our universe that we can learn, but it cannot trump community knowledge or precautionary government action.
        iv. All three must act in concert.

DIFFICULTIES OF COMMUNITIES DOING DATA-DRIVEN OR OTHER EJ SCIENCE IN THE CURRENT POLITICAL CLIMATE

1. INCREASED GOVERNMENT RESTRICTION AND CORPORTE POLITICAL INFLUENCE
    a. Scientists with strong corporate ties dominating government science advisory panels

b. Increased difficulty obtaining FOIA information in many arenas. The already time consuming and bureaucratic FOIA process has now been made more difficult or impossible in some cases.
c. Former Right-To-Know information pulled from government websites.

2. ENHANCED ROLES OF ACADEMIC IRBS WHICH HAVE LITTLE OR NO RELATIONSHIP TO, OR KNOWLEDGE OF, THE COMMUNITIES BEING RESEARCHED, including culture, language, values, etc.
3. ROLE OF MULTIPLE GOVERNMENT SECURITY AGENCIES IN APPROPRIATING SCARCE PUBLIC HEALTH RESEARCH DOLLARS FOR COUNTER-TERRORISM AND IN RESTRICTING DATA COLLECTION
    a. IN THE "TRAFFIC AND SCHOOLS" RESEARCH PROJECT, NYPD HAS REFUSED APPROVAL OF PERSONAL MONITORING BACKPACKS ON THE STREET OR IN THE SUBWAYS
        i. WE WERE TOLD WE NEEDED APPROVAL OF BOMB SQUAD, COUNTERTERRORISM TASK FORCE, NYS OFFICE OF NATIONAL SECURITY, SPECIAL OPERATIONS, ETC. WHICH WOULD NOT BE POSSIBLE TO OBTAIN.
        ii. INTERPLAY OF BACKGROUND "RACIAL PROFILING" OF YOUTH OF COLOR AND NEW SECURITY APPARATUS EFFECTING ABILITY TO CONDUCT RESEARCH.
        iii. PERSONAL MONTITORING WAS THUS NOT DONE THIS SPRING, CHANGING OUR TIMELINES, CREATING MUCH MORE WORK FOR SCIENTISTS WHO NOW MUST REDESIGN PERSONAL MONITORING DEVISE, MAKING IT SMALLER, BUT LESS SCIENTIFICALLY PRECISE AND DEPRIVING STUDENTS OF PERSONAL MONITORING EXPERIENCE.
4. INCREASED UNIVERSITY TUITION AND ROLLBACKS OF AFFIRMATIVE ACTION WHICH REDUCE THE ABILITY OF WORKING CLASS AND POOR PEOPLE OF COLOR TO OBTAIN MAINSTREAM RESEARCH AND SCIENTIFIC SKILLS

CONCLUSIONS

WHAT KINDS OF RESEARCH AND RESEARCH CONTEXT DO WE WANT TO SEE?

1. Concern for and relationships with the community that go beyond the boundaries of a grant.

2. Open communication between “scientists” and community members that recognizes the value of community knowledge and experience.
3. An engaged and active community that is willing and able to not just be active recipients of “knowledge,” or the means by which researchers gain access to community members and institutions, but which participates in the development of questions, the research protocol, the collection and interpretation of data, and the conclusions drawn. These community members will challenge the preconceptions, culture, perceptions, and inferences of the researchers all the way, and will add invaluable knowledge of their community, its culture, power dynamics, organization, as well as practical knowledge of the real world which researchers sometimes lack. This knowledge is critical for the accuracy and success of the research.
4. We want to see more science which not only documents the harms of pollution, but documents the success of pollution prevention. A good (not asthma) example is the recent study by researchers at the Children’s Environmental Health Center at Columbia which documented the increase in newborn head circumference after the EPA banned two toxic pesticides.
5. We want to see more science which documents the impact of multiple exposures, including in the case of asthma, for example, exposures to outdoor pollution and poor indoor air quality from deteriorating housing, effects of community exposures to both point and mobile sources, the relationship between the exposure to pollutants and increased social and other environment stressors.
6. We want research framed by the precautionary approach, and government willing to act on it; not self-perpetuating research that just leads to more research.