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Appendix 1

Contested Illnesses Research Group: Nuts & Bolts and Lessons Learned

Laura Senier, Rebecca Gasior Altman, Rachel Morello-Frosch, and Phil Brown

The Contested Illnesses Research Group (CIRG) was established in 1999 with funding from the Robert Wood Johnson and the National Science Foundation. The original project studied contestation over environmental factors in asthma, breast cancer, and Gulf War illnesses. Today, with new funding, new faces, and new research areas, CIRG meets weekly, bringing together faculty, postdoctoral fellows, and graduate and undergraduate students from sociology, anthropology, ethnic studies, community health, and science studies to discuss ongoing work. Often enough our alumni join in. We host visits from outside scholars and collaborate with scholars at other institutions (including the group's own recent graduates, scientists at Silent Spring Institute, Boston University, and the University of California-Berkeley). We also work with a variety of environmental health and justice groups that do community organizing and policy work (such as Communities for a Better Environment in Oakland, California).

We do not merely study citizen-science alliances, but actively participate in them, and work to ensure that the alliances we engage in benefit the communities we study, as well as advancing our own theoretical formulations. Like many scholars before us, we have found that the best way to learn is by doing. Over the last eleven years, by doing, we have learned many lessons. For the benefit of researchers who want to pursue similar work, here are eight of them.

Key Lesson 1: *Today's research participant is tomorrow's research partner.*

Policy ethnography often leads to collaboration with groups that were initially the focus of our research. More recently, our work on contested environmental illnesses and citizen-science alliances segued into participation in novel research collaborations among environmental health and justice activists, environmental scientists, and social scientists.

In 1999, the contested illness project included Silent Spring as a research site to examine disputes over environmental causation of breast cancer. Over time, our relationship grew into a productive and ground-breaking research partnership. In 2004, we further developed this partnership with Silent Spring Institute and Communities for a Better Environment in a project linking breast cancer advocacy with environmental justice activism, to conduct personal exposure assessments of hormonally-active pollutants found in home environments from consumer products, industrial emissions, and transportation sources. This community-based participatory research entailed collaborating with community members on the design and implementation of the study and reporting our findings back to participants and the community. Community activists were trained to collect air and dust samples to assess indoor and outdoor levels of pollutants, especially endocrine disruptors, which have been linked to breast cancer, reproductive and neurological anomalies, and other health outcomes. Silent Spring Institute's long record of participating in citizen-science alliances led to our new research partnership to focus on the ethical issues associated with the practice of reporting environmental study results to individual study participants.

Key Lesson 2: *Fortune favors the researcher who has cultivated community relationships.*

Serendipity can provide opportunities for the application of existing resources and infrastructure to advance intellectual and policy goals, but a “directed serendipity” such as we experience is made possible through the cultivation of relationships with community partners. As one example: through an ongoing research project with the Massachusetts Committee on Occupational Safety and Health on labor unions and environmental activism, CIRG learned about a new project that MassCOSH was working on with the Boston Urban Asthma Coalition. Our existing research collaboration made us aware of a new, related research opportunity, and we were able to devote graduate student research time to study this project. As related in Chapter 10, we helped MassCOSH and their partners evaluate their campaign to introduce environmentally-friendly cleaning products into a public school system. This work led not only to a report that we wrote for MassCOSH, in which we summarized our evaluation of the program, but also to a peer-reviewed journal article. While serendipity could be seen as the most proximate cause of our involvement in the green cleaners project, we found ourselves in a position to work on it because we had previously invested in relationships with the people and organizations that were involved in the project.

Key Lesson 3: *Share the data with participants.*

The documentation of the policy ethnography process for participants helps to create and reinforce connections between scholars and activists, and helps to disseminate important information to concerned audiences. The Household Exposure Studies on Cape Cod and Northern California are examples of how important it is to share data with participants. In this instance, our research collaborative shared information with study participants and the communities in which they lived. In earlier projects, we shared our findings with the

organizations that we studied, which led to further conversations, and in turn deepened our relationship and created further opportunities for collaboration, as described previously.

Our team's efforts to outline strategies for planning individual-level reporting of personal exposure information have been influential in other locales as well, ranging from academic to government run biomonitoring projects that monitor pollutants in human bodies. We believe that participants have the right to have access to data that was gathered from them and their community, should they choose to receive it. This helps them make informed decisions about whether and how to respond, and in this instance, democratizes the scientific process.

Key Lesson 4: *Share methods with other researchers.*

The development of policy ethnography as a methodological approach has helped build a network of scholars who are aware of and engaged in this type of research. It is our hope that this burgeoning network of scholars will not only continue the practice of policy ethnography to produce scholarship that will advocate for communities burdened by environmental injustice, but also will help to improve, refine, and expand the methodological sophistication of policy ethnography tools. Many of our articles detail the collaborative nature of our work, sensitizing a wide variety of scholars to community-based participatory research and community-engaged activities. We believe that researchers need to share their philosophy and experiences with others in their immediate departmental circles and scholarly communities, so that others can see the benefits and responsibilities of these approaches. For example, we designed a colloquium series on public sociology and community-based participatory research for the Brown Sociology department, which was well-attended and fostered thought-provoking conversations in the Department of Sociology and other departments.

It is important to demonstrate to graduate students as well as faculty that they can publish high quality articles in top journals, based on the policy ethnography approaches we use. The Contested Illnesses Research Group is a unique forum where students can explore both the theoretical and applied elements of environmental health and social movement scholarship. Students who have participated in the group have had opportunities for authorship on journal articles and book chapters. They also have had ample opportunity to take the lead on writing projects and reports that are used by our community-based partner organizations, and to work on collective grant-writing. Students have organized several of the outreach initiatives outlined above, including work with the Toxics Action Center, a grassroots support group based in Boston, Massachusetts, with regional offices in every New England state, and with community groups served by the Brown Superfund Research Program Outreach activities.

Key Lesson 5: *Engaging community organizations in the scientific process will lead to even more community-directed research.*

Scientific capacity-building can enable organizations to successfully launch their own data-collection initiatives that help inform community organizing and policy advocacy strategies. On a local level, Communities for a Better Environment chose to continue the scientific work in Richmond by conducting their own survey to assess community perceptions of environmental health and neighborhood stressors. Our team assisted CBE in writing a successful Avon Foundation grant to fund work on this community survey. We also assisted in developing the questionnaire and in developing field methods and data analysis. Not only did this endeavor provide valuable health data, but it allowed CBE to leverage the survey to advance their

organizing efforts in several Richmond neighborhoods and to make productive linkages with other community organizations in the area.

Key Lesson 6: *Policy ethnography has practical impact.*

Our work shows that broad-based projects can be developed to assess the policy, legal, and regulatory impacts of community-based participatory research in environmental health. For example, we recently embarked on a study of human biomonitoring, a scientific approach for characterizing environmental pollutants in human samples such as blood or urine. In this research, we examine the scientific, ethical, and public policy implications of this emerging body of science and its recent proliferation in academic and environmental health advocacy arenas. This kind of research can assess of the rigor, relevance and reach of scientific research in environmental health. Under the auspices of a new NSF grant, we explore biomonitoring science in the three arenas where it is most typically conducted and debated: national-level population surveillance; state-based biomonitoring studies; and place- or community-based studies that investigate local environmental problems. Engaging with researchers and activists in these various arenas has augmented our expertise in shaping discussions about ethical report-back approaches, and made our project more visible to the growing community of people doing biomonitoring and household exposure studies. For example, one member of our team has been invited to participate in planning the California biomonitoring program. Our partners at Silent Spring Institute were invited to present our approach to reporting back individual exposure data at the grantees conference of NIEHS' Breast Cancer and the Environment Research Centers and to a special workgroup of the CDC.

Our findings in the household air and dust monitoring project uncovered very high rates of flame retardants, especially PBDEs, in (human body fluids) in Cape Cod, and then in air and dust in California, most likely due to that state's stringent but misinformed, furniture flammability standards. This finding led us to develop additional research on flame retardants as a class of chemicals. It also promoted new collaborations between our team and scientists who are trying to change California policy, prevent federal policy from adopting dangerous flammability standards, and prevent the adoption of international protocols that would add billions of pounds of flame retardants to electronics.

Another practical outgrowth of our policy ethnography work on health social movements has been a research focus on coalitions among activist groups concerned about health and the environment, particularly between the labor and environmental movements. Although recent history suggests an adversarial relationship between labor unions and environmental groups, a longer history points to a mutually supportive relationship between unionists and others concerned with the health effects of chemical exposures. Our own work has shown that when so-called blue-green coalitions form around a shared health concern, they more easily bridge these historic, ideological divides to form viable, successful coalitions. The broader area of blue-green alliances is discussed in "Labor-Environmental Coalition Formation: Framing the Right-to-Know" (Chapter 11).

Key Lesson 7: *Build community capacity to sustain research and outreach activities.*

One of the reasons CIRG has been able to cultivate long-term partnerships for both research and outreach is that we have worked for years to build the long-term capacity of community organizations. This has allowed our community partner organizations to establish

sustainable organizational structures that enhance the effectiveness of our research initiatives when they are linked to advocacy and organizing efforts. We started our work with individual community-based organizations in Rhode Island as early as 2003, but very quickly formulated a goal of creating a statewide network of community groups that would cooperate on campaigns for environmental health and social justice. In 2007, the Environmental Justice League of Rhode Island (EJLRI) was launched, with grant support from the U.S. Environmental Protection Agency and 10 community groups as participating members. The CIRG helped to promote the EJLRI's genesis in three specific ways: first, by helping community groups connect to one another; second, by connecting the emerging statewide network of community groups to similar advocacy networks elsewhere in the region and across the country; and third, by providing concrete and tangible university resources to build community capacity.

Long before beginning our work in Rhode Island, the CIRG team had a relationship with Toxics Action Center, a non profit agency based in Boston that has supported more than 500 organizations across northern New England in fighting environmental pollution. In 2003-2004, one of our students wrote a master's thesis in which she interviewed activists who received support from TAC in order to learn more about the pressures and difficulties faced by first-time activists (Altman 2004). This work brought the CIRG team in touch with community groups in Rhode Island working on environmental campaigns. Although our Rhode Island neighbors knew of Toxic Action Center's existence, we believed that would clearly benefit from a more local forum where they could seek leadership development support and technical assistance. As a result of this work, CIRG began working to help Toxics Action Center establish a presence in Rhode Island. The CIRG team helped TAC obtain foundation support from the Cox Charitable Trust to establish an office in Rhode Island, and developed leadership training and capacity

building workshops to train and sustain grassroots leaders in what can often be protracted campaigns.

We therefore began working to create a forum where community groups in Rhode Island could connect to other people working on similar issues. Communities throughout Rhode Island are fighting lead poisoning; high rates of childhood asthma; substandard housing in subsidized housing developments; inappropriate siting of public schools on contaminated land; and toxic waste regulation, reduction, and cleanup. To help communities connect with one another, CIRG began organizing workshops under the organizing name of the Providence Environmental Justice Education Forum (PEJEF) in 2004. We used grant support from an NIH-funded project, the Collaborative Initiative for Research Ethics in Environmental Health, to hold quarterly meetings where groups could come together to meet one another, share stories, and cooperate on common problems and challenges. Some of the participants in these forums were working on contamination in residential communities, and helped one another with organizing and protest activities. For example, two communities in southern Rhode Island were fighting air and water pollution caused by a local textile and dye firm. These community groups helped one another form bucket brigades to capture air quality data that they could use in their common campaign to get the company to clean up their operations. They were ultimately successful, and negotiated a settlement with the corporate polluter that included equipment upgrades to reduce the amount of pollution emissions and funds for a comprehensive health assessment of the surrounding community. These community groups reached out to their neighbors in Tiverton, Rhode Island, where more than 100 property owners learned that their homes were built on contaminated fill. The PEJEF meetings thus became one means through which community groups could learn

about other similar problems in the state, sometimes sharing strategies and tactics, but also simply offering their neighbors support and encouragement.

Because these campaigns are often so long and often so highly technical, the CIRG recognized that our community partners needed specialized advice and technical assistance. We worked to provide this by linking our emerging network to similar networks elsewhere in the region and across the country. We brought organizers from two Boston-based environmental advocacy groups—Toxics Action Center and Alternatives for Community and Environment—to Rhode Island for strategy and training sessions. They offered advice on specific campaigns, but also spoke about what resources and vision would be needed to build a long-range and sustainable organizational form. We also connected the PEJEF with the Connecticut Coalition for Environmental Justice, another emerging, regionally-based environmental justice group. Finally, we connected the emerging Rhode Island coalition to anti-toxics groups on the national scene, including the Center for Health, Environment, and Justice (CHEJ). We invited Lois Gibbs to Rhode Island to speak to activists who were fighting pollution in residential communities, but also those who were campaigning against the construction of public elementary and secondary schools on or near contaminated land. We helped connect our community partners and their attorneys at Rhode Island Legal Services (RILS) to CHEJ's growing network of school environmental health activists. Attorneys at RILS and some Brown students conducted a thorough analysis of state laws concerning school siting and found that twenty states have no laws of any kind prohibiting construction of schools on or near contaminated land. In these various ways, the CIRG has helped connect the growing coalition of Rhode Island-based environmental justice groups to regional and national networks, and to contribute to the dialogue about how contamination is affecting communities across the country.

Whenever possible, CIRG supported the emerging statewide network by providing specific, concrete resources, including skill-building opportunities, but also personnel and financial support when necessary. For example, we ran skill-building workshops for PEJEF members, on topics ranging from how to communicate with the media to grant writing. Two of our member groups received grants from the EPA's Healthy Communities Program after one of our grant writing workshops. We also provided personnel support by assigning graduate and undergraduate students to service learning projects in these communities. Our students analyzed government and scientific reports, designed websites, wrote and translated pamphlets, organized walk-a-thons, and coached middle schoolers in public speaking. These students were sometimes CIRG members, but also were recruited to serve through service learning assignments in individual Brown courses. We also recruited students to do work in communities through the Community Outreach Core of Brown's Superfund Research Program grant, or through the Swearer Center for Public Service. Finally, and not to be overlooked, we provided financial support, through several different mechanisms. As we have described, we have often written community-based organizations into our grants as partners, so that they receive a share of the grant to sustain their local operations. This allows them to hire and retain staff, secure office space, and support operating budgets. We have also, however, budgeted in our grants for public meetings and community outreach so that we can reach a more general public audience. And we have helped our community partners when they have written grants to secure independent funding. We assisted the EJLRI in their first grant application to the USEPA CARE program, and celebrated with them when they were awarded a \$100,000 grant to provide general support for its work. We also helped the EJLRI obtain a special grant from the national program office of the Superfund Research Program. The combination of these two grants provided salary support

for two staff members and a graduate student research assistant, all dedicated to the EJLRI's programmatic activities.

Conclusion

We believe that outreach activities are most likely to be effective when developed in response to the needs and interests of community groups, and we have therefore worked hard to tailor our outreach efforts to the needs of the groups with whom we are working. With our diverse connections, we have been able to tap into many groups and networks, and to demonstrate the importance of environmental health and environmental justice as organizing frames that are vitally important to the community groups we serve. While the work of our group has been oriented around serious theoretical and empirical investigation of various aspects of environmental health and health social movements, we have been conscious of the need to rise from the level of abstraction to connect these theories with practice, often providing concrete support to help our community partners in their campaigns.

For a list of publications and information on our current research please visit the website for the Contested Illnesses Research Group (<http://www.brown.edu/contestedillnesses>) and the Superfund Research Program--Community Outreach Core (<http://www.brown.edu/Research/SBRP/coreE.shtml>)

References

Altman, Rebecca Gasior. 2004. "Biographical Disruption and Local Anti-Toxics Activism." MA Thesis. Brown University Department of Sociology.