

This is a draft discussion paper that explores ethical issues surrounding community-based organizations investigating environmental health hazards in high-risk housing and using the results in their advocacy. It was written by Alliance To End Childhood Lead Poisoning, Executive Director Don Ryan with assistance from an ad hoc committee comprised of other CEHRC staff and CEHRC Local Leadership Council members. It incorporates suggestions from other local leaders, as well.

# Respecting and Protecting the Rights of Families and Tenants

## *Ethical Issues Arising Out of Testing for Housing-Related Health Hazards as an Organizing and Advocacy Tool*

### *Introduction and Purpose*

Around the country, community-based organizations are planning projects to train staff and community members how to document health hazards and housing code violations in high-risk housing and to use the results in organizing and advocacy campaigns. The Community Environmental Health Resource Center (CEHRC) is now gearing up to provide technical support and assistance to interested local groups, including developing step-by-step instructions for assessing lead and other housing-related health hazards.

Assessing health hazards in housing necessarily involves visually inspecting homes and collecting environmental samples for analysis. These activities inevitably raise sensitive issues related to residents' privacy and other rights. The recent controversy over lead poisoning prevention research studies in Baltimore has called attention to related issues, specifically the responsibilities researchers owe to those whose homes they study. There are important differences in the ethical issues posed by research studies performed by scientists and efforts by community-based groups to identify hazards as an advocacy tactic. Indeed, the central purpose of CEHRC is to empower communities at risk by providing access to new tools and strategies for holding landlords and government agencies accountable and winning needed policy changes. Nevertheless, it is important that community-based organizations carefully consider a number of ethical issues in planning and carrying out projects to identify environmental hazards in high-risk housing and advocacy campaigns that use the results.

The purpose of this paper is to foster discussion among community organizations and residents, not to establish legally binding standards or to mandate action. After further refinements based on comments received, this paper will offer a reference and resource to leaders and staff of community-based organizations interested in assessing health hazards in housing and that the principles articulated will help guide project planning and execution.

### *A New Use of Environmental Sampling*

CEHRC is a new resource to community-based organizations working for social justice in communities at high risk for lead poisoning, asthma, and other health problems of environmental origin. Substandard housing poses environmental health hazards to low-income families due to the failure of multiple systems: poor maintenance by landlords; unprotective laws and codes; lax enforcement by government agencies; and insufficient subsidies for decent, safe, and affordable housing. All too often, housing-related environmental hazards go unexamined, unidentified, and ignored until human health has been harmed.

Protecting residents and their children requires detecting and correcting hazards in their homes before health problems develop. Traditionally, the tools to assess such hazards have belonged to “experts,” but recent technological advances have reduced the cost and simplified their use. CEHRC bridges the gap between science and communities at risk by providing tools, training, technical assistance, strategy advice, and grants to help trained local project staff identify and address health hazards in high-risk housing.

Community-based organizations working with CEHRC do not collect data on health hazards simply for the sake of science or for the theoretical benefit of future generations. Instead, this application of environmental testing offers community-based organizations the ability to document hazards as a means to trigger action to correct substandard conditions in the homes sampled, in neighboring homes, and throughout communities at risk.

Individual families stand to benefit from the knowledge about health hazards in their homes that environmental testing can reveal. But CEHRC’s central purpose is to explore how data documenting such hazards can be used as an organizing and advocacy tool to hold landlords accountable, change public policy, and strengthen government programs. In fact, most families cannot effectively protect themselves and their children from health hazards in substandard housing through changes in their day-to-day behavior (e.g., diet, housecleaning, and hygiene), and most very low-income families do not have the resources to relocate to safe housing. Even if families have the ability and means to move, safe and affordable housing is scarce in many neighborhoods in many cities.

### ***Putting Families’ Rights First***

CEHRC partners with local organizations that have authentic ties, shared values, and a keen understanding of their community’s assets and needs. However, the fact that a responsible and representative community-based organization seeks to identify health hazards expressly to help families at highest risk does not rule out the possibility that unintended consequences could bring harm to these very families. The following possibilities are reminders of the need to respect and protect individual rights:

- A landlord might evict a family in retaliation to notice about health hazards or board up his property instead of making mandated repairs,
- A landlord might aggravate hazards by using unsafe work practices or harass tenants by making only partial repairs,

- A resident might misunderstand the test results and abandon the property without good cause or adequate compensation,
- A family might be stigmatized after neighbors overhear information about health hazards in their home, or
- Undocumented residents might be deported.

The ability to identify a health hazard in a resident’s home is a tremendously powerful tool, the use of which requires care, forethought, and sensitivity. The following central principle must underpin the design and conduct of environmental sampling projects undertaken by community-based organizations:

*The rights of individual residents whose homes are investigated must always be paramount to the organizing and advocacy strategies and tactics designed to benefit these families, their neighbors, and the larger community.*

When hazards are identified, organizations should guard against inadvertently shifting responsibility for corrective action to tenants. While all parents and caregivers want to do whatever they can to protect their children, rental property owners have a legal duty to maintain properties in safe and sanitary condition and government agencies bear responsibility for ensuring that laws and codes are enforced. In cases where parents can take steps to reduce risks, they deserve accurate information about temporary measures. But achieving systemic, long-term solutions depends on residents understanding their rights and organizing their communities to hold those who bear responsibility accountable for taking corrective action and instituting preventive measures.

### ***Outline of Major Issues***

This paper organizes and discusses ethical issues related to environmental sampling for advocacy and organizing in four broad categories:

- Involving Residents in Projects and Campaigns
- Respecting Families’ Property, Time, and Safety
- Informing Residents of the Results
- Using Data Responsibly to Organize and Advocate for Prevention

### ***Involving Residents in Projects and Campaigns***

Scientists doing research recognize the legal duty to secure the “informed consent” of individuals participating in a study. While securing written consent may provide a researcher with legal protection, community-based organizations documenting hazards for organizing

and advocacy should strive for the higher standard of involving residents meaningfully in projects to assess health hazards in their homes and in organizing and advocacy campaigns that leverage the results. Community leaders and concerned residents should be involved to the maximum extent possible in all stages of project planning, from setting goals and objectives to designing strategies and tactics to trigger corrective action.

Before an organization begins to investigate hazards in any home, it is essential that the residents understand what is involved, what they can expect from the organization, and what is expected from them in return. A written agreement expressed in plain language is the best vehicle to communicate key information and document this understanding. (Translation should be provided for residents' whose primary language is not English.) While the formality of a written agreement could pose a barrier to trust in some relationships, such an agreement clarifies mutual expectations and may serve to enhance the credibility of the test results. Far more than a technicality, the dialogue that results in this agreement is integral to educating residents about health hazards in their community, building trust, engaging community members in the project, and organizing to pursue larger objectives.

CEHRC has developed a Draft Resident Agreement (see Attachment A), to assist community-based organizations as they address key issues with residents, including the following:

- The objectives and rationale of the organization's project to assess environmental hazards in homes in the community, including how documenting health hazards caused by substandard housing can be a positive step toward corrective action;
- What hazards will be assessed, why they matter, and what hazard assessment tools will be used;
- The risks, if any, associated with the testing along with an explanation of any precautions residents should take. (It is vital that residents not confuse the significant health risks often posed by substandard conditions in their homes with the risks, if any, of assessing these hazards. While these hazard assessment protocols should pose no threat to residents' health, any potential risks should be carefully explained along with steps needed to ensure the validity of the test.);
- What kind of information will be generated, when the results will be available, and how the results will be shared with the resident;
- The resident's control over release of data that could identify the resident or their address and how the organization plans to use "macro data" for organizing and advocacy;
- What information or assistance the organization may be able to provide to assist the family.

It is assumed that community-based organizations will investigate environmental hazards at no charge to low-income residents. Charging a fee fundamentally changes the nature of the relationship and may trigger additional requirements in some states.

### ***Respecting Residents' Property, Time, and Safety***

Being welcomed into someone's home to assess environmental health hazards is a privilege that requires project staff to honor the trust extended and to respect the resident's property, time, and safety. This involves adhering to some basic practices, including the following:

- Ensuring the resident's understanding of the process before beginning to investigate hazards – a key step being the signed written agreement;
- Scheduling visits that are convenient for the resident, allowing ample time for full explanations, and providing contact information for follow-up questions;
- Respecting cultural practices and individual household practices;
- Following all necessary precautions to protect residents and their belongings while assessing hazards;
- Allowing residents to decline answering a question, having photographs taken, or having some test procedure performed;
- Avoiding tests that would damage the property, unless the owner consents; and
- Taking away all testing materials, supplies, and refuse for proper disposal.

### ***Informing Residents of the Results***

Organizations should provide a written report of hazard assessments results (both positive and negative) to residents in a timely manner and offer to explain the results and answer questions in person. Results should be presented and explained in a way that is meaningful and understandable to the family (in the family's primary language):

- If government or industry standards exist, provide these as standards for comparison.
- Whenever a hazard is found, provide the resident with information about steps that can be taken to reduce, control, and prevent hazards. CEHRC is developing easy-to-read materials that outline strategies for hazard control and prevention. In some cases, families can take low cost measures to ameliorate housing-related health hazards. In other cases, it may be hazardous for occupants to attempt to take corrective measures themselves.

- Do not exaggerate the risks found, as creating unwarranted fears causes anxiety that itself imposes a burden on the family.
- If the results do not indicate a hazard, guard against leaving the family with a false sense of security. CEHRC test protocols are geared to flag serious hazards but do not take enough samples to unconditionally declare a property “safe.”
- Inform residents of their legal rights as well as sources of assistance, such as legal services, as rental property owners have a legal duty to provide safe housing, and government agencies bear responsibility for enforcing laws and codes.
- Be prepared to provide advice and/or assistance to residents when an extreme hazard is identified that may pose an immediate threat to life or safety. For example, extremely high levels of carbon monoxide warrant immediate action.
- Encourage residents to unite with others whose homes contain similar hazards to win progress on a broader front and be prepared to provide organizing assistance as needed and appropriate.

### ***Using Data Responsibly to Organize and Advocate for Prevention***

Landlords and government agencies cannot be held accountable unless data documenting the presence of health hazards are shared beyond the individual residents whose homes are tested. Residents should be included to the maximum extent possible both in designing strategies to leverage data for maximum benefit and in actually releasing the information. To ensure that residents’ privacy and rights are protected in using data for advocacy and organizing, the important distinction must be recognized between “address-specific” information and data that do not reveal the specific premises tested or otherwise identify specific tenants.

Consistent with the written agreement with the resident, local groups may freely release and report data that are aggregated and analyzed so that residents’ names and addresses are not revealed or ascertainable. For example, an organization can compile data collected in units throughout a geographic area to document community-wide housing-related health hazards. Reporting such “macro data” at the block, census block group, census tract, or ZIP code level can effectively support broad advocacy campaigns, such as passage of a new ordinance or increased public funding for housing rehab in the identified neighborhood. Tools for analyzing and presenting such aggregate data will be shared through CEHRC.

In most cases, however, community-based organizations will find that citing data for specific properties provides much more pointed, vivid, and compelling documentation of hazards to trigger overdue action. Such address-specific information can also serve as a powerful lever for organizing and advocacy in multiple ways, including:

- Discovering that health hazards are present in many units in a building or housing complex can bring residents together in common cause, increasing individuals’ power through numbers;

- Putting a landlord on notice about the presence of a lead hazard in a specific unit engages the federal disclosure law, which requires the landlord to disclose the hazard to future tenants in the building or face stiff federal fines and penalties; and
- Disclosing multiple code violations identified in an apartment building, complex, or neighborhood can pressure government officials to step up code enforcement.

Because reporting address-specific data on health hazards or code violations to a landlord, government agency, or the media could result in unintended adverse consequences to tenants, organizations should obtain the concurrence of any affected residents in what data will be released, to whom, by whom, and when. As part of its outreach to residents, the organization should explain the possible risks involved in notifying the landlord, a government agency, or the media about documented hazards. Organizations should also be prepared to assist the family in dealing with any negative consequences. If the organization does not have the capacity to do so itself, it should coordinate arrangements in advance with other organizations to provide assistance such as legal services. In determining whether or not particular data should be considered “address-specific,” groups should err on the side of caution.

If a resident is fearful about the disclosure of the address, other options are still available for using that data for broader advocacy and organizing.

- Tenants in an apartment building or development can encourage their neighbors to have their units tested as well. Such a building-wide or development-wide approach spreads the risks among multiple tenants, while providing a tool for organizing to win a common victory against a bad landlord.
- An organization fighting an owner of multiple problem properties can investigate a few units in each building to document a pattern of deferred maintenance and neglect to trigger targeted code enforcement.
- The organization can postpone reporting a health hazard to the landlord or government agency until after the resident has moved and the unit is vacant;

Staff and volunteers of a community-based organization investigating environmental health hazards in substandard housing need to be prepared for a variety of unanticipated situations, including: drug use, domestic violence, child abuse, and health and safety hazards unrelated to environmental hazards. Presumably, evidence of some of these factors would disqualify a property. Possibly evidence of some of these factors might justify a report to the responsible government agency. Each local organization needs to respond based on its own policies and state and local laws. Decisions made in these matters may have significant implications for the group’s ability to build and retain the trust of community members.

Finally, organizations undertaking projects to assess health hazards in housing should seek to build capacity in the community and expand employment and economic opportunities. Community members should be compensated for their time doing assessments, and training

should be provided to build skills and open additional opportunities. Capacity to remediate (as well as assess) hazards should be built within the community by training community members and small contractors.

### ***Conclusion***

Most of these recommendations reflect the respectful relationships that effective organizations already share with members of their communities. Environmental sampling of communities, by communities, and for communities is a powerful and versatile tool for organizing and advocating for action to reduce health risks and meet pressing community needs. It is the very significance of these tools' potential to trigger change that demands careful attention to the ethical issues associated with testing for hazards in residents' homes.