



Lead-Free Kids New York

A Case Study in
Aligned Funding for
Environmental Health
Policy & Advocacy
Grantmaking



Executive Summary

Engage New York (ENY) is a statewide network led by philanthropy practitioners who learn and act together to advance equity and systems change. Through our efforts, we incubate opportunities for funders across the state to work together to design, pilot, and test approaches that move resources in ways that build their collective capacity to meet the needs of communities. This case study examines an aligned funding strategy undertaken by four community foundations to amplify their collective impact by launching the Lead-Free Kids New York Coalition, an advocacy coalition working to end childhood lead poisoning in New York State. We uplift this work because childhood lead poisoning is a racial justice issue and because it is an entirely solvable issue, provided we have the political will to do so.

WHY CHILDHOOD LEAD POISONING?

Young children exposed to lead may face a range of symptoms, including “...developmental delays, learning difficulties, irritability, loss of appetite, weight loss, fatigue, abdominal pain, vomiting, constipation, hearing loss, and seizures.”¹ This toxic legacy of lead does not impact all children equally, as there are significant racial and socioeconomic disparities in rates of childhood lead poisoning. A study published in 2020 found that nationwide, black children are 2.8 times more likely to have an elevated blood lead level than white children.²

WHY COMMUNITY FOUNDATIONS?

Given the geographic disparities in rates of childhood lead poisoning—which are strongly correlated to race—place-based funders are well suited for grantmaking and deep engagement where childhood lead poisoning is most pronounced. In New York State, four community foundations have taken a leadership position on lead poisoning issues in their regions: The Community Foundation for Greater Buffalo, The Central New York Community Foundation, The Community Foundation of Herkimer and Oneida Counties, and The New York Community Trust.

This does not mean that lead is not an issue in other parts of the State; rather, it highlights the four community foundations with the resources and dedicated staff to address this issue through their grantmaking portfolios. We encourage other funders to join our efforts since this is a statewide issue that needs more philanthropic support.

¹ “Lead Poisoning: Symptoms & Causes,” Mayo Clinic, <https://www.mayoclinic.org/diseases-conditions/lead-poisoning/symptoms-causes/syc-20354717>

² Deniz Yeter, Ellen C. Banks, and Michael Aschner, “Disparity in Risk Factor Severity for Early Childhood Blood Lead among Predominantly African-American Black Children: The 1999 to 2010 US NHANES,” *International Journal of Environmental Research and Public Health* 17, no. 5: 1552, 2020, <https://doi.org/10.3390/ijerph17051552>



THE PROGRAMMATIC CHALLENGE

The reduction in childhood lead poisoning resulting from direct-service grantmaking is limited by the broader policy systems in which those direct-service programs must operate. These limits are unlikely to be overcome without also addressing the structural barriers to ending lead poisoning that emanates from state policy.

THE PROGRAMMATIC SOLUTION

The funders recognized that no single community could “go it alone” to achieve these policy changes. Instead, coalition building was needed to harness the collective power of local service providers, grassroots organizations, impacted and affected individuals, public and environmental health experts, environmental justice organizations, and policy and advocacy organizations.

THE FUNDING CHALLENGE

The next challenge was marshaling the needed resources to advance the coalition-building and advocacy campaign strategy. In general, there are limited philanthropic resources for healthy housing & environmental health advocacy in New York State, and even more significant limitations on funding for lobbying.

THE FUNDING SOLUTION


Aligning funding across a coalition of funders increases the total grant award to an impactful amount. Consolidating application and reporting requirements across several foundations into one streamlined process also reduces grantee time spent on applications and reporting, thereby increasing the time available for their charitable activities. Furthermore, public charities, such as community foundations, are uniquely positioned to support advocacy, including lobbying. Given their diversity of funding sources and board membership, public charities may earmark a portion of a grant for lobbying.

LEAD-FREE KIDS NEW YORK’S IMPACT TO DATE

With the support of aligned funding, the Lead-Free Kids New York Coalition was established in October 2020. In November 2021, the Coalition secured the first legislative hearing on childhood lead poisoning prevention in over 25 years. Over the 2021-2022 legislative session, the Coalition secured the introduction of five bills; two passed in the Assembly, and another, the Safe School Drinking Water Act, was signed into law by Governor Hochul in December 2021.

CONCLUSION

Issues stemming from systemic inequity, such as childhood lead poisoning, cannot be solved through direct-service programming alone. Systems change requires the alignment of the public, private, and social sectors around a common goal and must often include changes to public policy and public funding. Parallel efforts to 1) build a coalition of grassroots advocacy organizations and 2) align grantmaking across a coalition of funders, are needed to commit the level of resources required over the long term to achieve systems change.



“If you steal
someone’s
IQ—and that’s
what lead does—
you’ve stolen
their future.”

RALPH SPEZIO, FORMER PRINCIPAL
ENRICO FERMI SCHOOL 17 ROCHESTER, NY

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Why Are We Still Talking About Childhood Lead Poisoning?

Health Effects

There is no safe level of lead for human exposure. Even low levels of lead exposure can cause irreversible neurological damage to the developing brains of children aged six and under, including loss of IQ, difficulties paying attention, and reduced academic achievement.¹ Lead is most often present in the form of lead dust from deteriorated paint, lead in soil,² and lead in drinking water. Other exposure pathways include lead in consumer products, food, medicine, and occupational exposure.³ Young children exposed to lead may face a range of symptoms, including "...developmental delays, learning difficulties, irritability, loss of appetite, weight loss, fatigue, abdominal pain, vomiting, constipation, hearing loss and seizures."⁴



for residential use in 1978.⁵ The federal government took additional action through the Clean Air Act and subsequent EPA regulations that required lead to be phased out of vehicle gasoline from 1973 until its completion in 1996.⁷ While lead was phased out of these and other mass-market products, the legacy of its use remains with us today. Research conducted at Columbia Law School's 2019 Health Justice Advocacy Clinic found "over 78.46% of New York's housing stock was built before 1980, meaning there are 5,370,020 occupied housing units in New York that contain possible lead-based paint hazards. Of these housing units, approximately 629,865 occupied units contain both children under six and possible lead hazards."⁸

History & Scope of Problem

In recognition of lead toxicity, New York State banned the sale of lead-based paints in 1970,⁵ with the federal government following suit and banning lead paint

1 "Childhood Lead Poisoning Prevention: Blood Lead Levels in Children," *Centers for Disease Control and Prevention*, <https://www.cdc.gov/nceh/lead/prevention/blood-lead-levels.htm>

2 Lead in soil oftentimes occurs because of deteriorated lead paint settling into the soil. However, sometimes lead in soil is the result of industrial contamination or the settling of leaded gasoline exhaust over many years.

3 "Childhood Lead Poisoning Prevention: Sources of Lead Exposure," *Centers for Disease Control and Prevention*, <https://www.cdc.gov/nceh/lead/prevention/sources.htm>

4 "Lead Poisoning: Symptoms & Causes," *Mayo Clinic*, <https://www.mayoclinic.org/diseases-conditions/lead-poisoning/symptoms-causes/syc-20354717>

5 Katrina Smith Korfmacher, Emily A. Benfer, and Matthew Chachère, "Lead Laws and Environmental Justice in New York," *NYSBA The Environmental Lawyer* 39, no. 1 (Fall/Winter 2019): 49

6 "Childhood Lead Poisoning Prevention: Sources of Lead Exposure: Lead in Paint," *Centers for Disease Control and Prevention*, <https://www.cdc.gov/nceh/lead/prevention/sources.htm>

7 Jessie Stolarik, "Fact Sheet: A Brief History of Octane in Gasoline: From Lead to Ethanol," *Environmental and Energy Study Institute*, March 30, 2016, <https://www.eesi.org/papers/view/fact-sheet-a-brief-history-of-octane>

8 Emily Benfer et al., "The Cost of Childhood Lead Poisoning in New York," *Columbia Law School Health Justice Advocacy Clinic*, 2019, https://web.law.columbia.edu/sites/default/files/microsites/clinics/health-advocacy/new_york_cba_1_1.pdf



Columbia's Health Justice Advocacy clinic was also able to project how many children likely have an elevated blood lead level in New York State:

According to the Centers for Disease Control and Prevention (CDC), 6.19% of New York State's children under six and 2.21% of New York City's children under six had blood lead levels above the CDC reference value of 5 micrograms per deciliter ($\mu\text{g}/\text{dL}$) in 2011 (New York State) and 2014 (New York City), these were the most recent years with complete data available. Applying this percentage to the state's under six population, it is estimated that approximately 80,215 children are likely to have elevated blood lead levels (EBLL) above the CDC's reference value.⁹

Using this information, the Clinic also estimated the societal costs of lead poisoning in New York:

For one cohort of children ages one to two years old who are estimated to have EBLLs above the CDC reference value, the costs could be as high as \$904,386,669.10 with children in the Housing Choice Voucher (HCV) program accounting for \$106,835,594.44 of these costs. These costs accrue each year to children when they first develop lead poisoning and repeat themselves every year as new children ages one to two years old develop lead poisoning. The potential costs for a single birth cohort of children in New York state age one to two years old include:

- \$790,680.02 in costs associated with immediate medical intervention
- \$4,850,701.65 in costs associated with treatment of lead-related ADHD
- \$3,061,141.32 in parental work loss due to time taken off to care for a child with an EBLL above 5
- \$2,233,487.70 in costs associated with additional special education services for children with lead poisoning
- \$893,450,658.41 in potential earnings over a lifetime

Taxpayers would shoulder up to 26.72%, or \$241,674,245.64, of these total costs.

These cost estimates do not include pain and suffering for the child or criminal justice costs. Additionally, these estimates do not include EBLLs between 2 $\mu\text{g}/\text{dL}$ and 5 $\mu\text{g}/\text{dL}$ and, according to a 2019 study by Altarum,¹⁰ the costs associated with children who have EBLLs above 2 $\mu\text{g}/\text{dL}$ could be as high as \$6.4 billion and impact 12% of all births in New York State in 2019.¹¹

⁹ Emily Benfer et al., "The Cost of Childhood Lead Poisoning in New York," *Columbia Law School Health Justice Advocacy Clinic*, 2019, https://web.law.columbia.edu/sites/default/files/microsites/clinics/health-advocacy/new_york_cba_1_1.pdf

¹⁰ "Preventing Childhood Lead Exposure: Costs and Benefits," *Altarum Institute*, 2019, <http://valueofleadprevention.org>

¹¹ Emily Benfer et al., "The Cost of Childhood Lead Poisoning in New York," *Columbia Law School Health Justice Advocacy Clinic*, 2019, https://web.law.columbia.edu/sites/default/files/microsites/clinics/health-advocacy/new_york_cba_1_1.pdf



Environmental Racism & Housing Discrimination

The toxic legacy of lead does not impact all children equally as there are significant racial and socioeconomic disparities in rates of childhood lead poisoning. A study published in 2020 found that nationwide, black children are 2.8 times more likely to have an elevated blood lead level than white children.¹² A 2019 New York State Bar Association Journal article examined New York State's disparities, having found that:

In 2005, [New York State Department of Health] reported that 54% of the children identified with BLLs over 10 µg/dL lived in just 68 of the over 1600 zip codes in the state. Most of these 'high-risk zip codes' encompassed communities of color in older urban areas. For example, analysis of census data in Rochester showed that Black and Latino children were far more likely than white children to live in one of its five 'high-risk zip codes.' The distribution of lead poisoning along racial and socioeconomic lines strongly affirms that lead is an issue of environmental justice in New York.¹³

Researchers uncovered similar findings for other cities throughout the country. For example, one study on the racial ecology of lead poisoning in Chicago from 1995-2013 found:

...the racial ecology of what we call toxic inequality is partially attributable to socioeconomic factors, such as poverty and education, and to housing-related factors, such as unit age, vacancy, and dilapidation. But controlling these factors, neighborhood prevalence rates of elevated BLL remain closely linked to racial and ethnic segregation.¹⁴

In examining why New York's cities have such stark disparities in childhood lead poisoning rates along the lines of race and class, it is impossible to ignore the long history of racial discrimination in federal housing policy. 1930s New Deal housing policies—especially redlining practices by the Home Owners Loan Corporation (HOLC), which resulted in the exclusion of entire neighborhoods of color from accessing the then-newly created and federally insured 30-year mortgage—created significant and persistent racial disparities in access to healthy and affordable housing.¹⁵ In most cities with a history of redlining, the correlation between the redlining “grade” a neighborhood received and its current rates of childhood lead poisoning are undeniable.¹⁶ Across New York State, one can see most formerly redlined neighborhoods have many homes in disrepair, including exposed lead hazards, due to the inability of many residents to buy or refinance real estate in their neighborhood.¹⁷ For example, redlined census tracts can see lead poisoning rates as high as 40% in

12 Deniz Yeter, Ellen C. Banks, and Michael Aschner, “Disparity in Risk Factor Severity for Early Childhood Blood Lead among Predominantly African-American Black Children: The 1999 to 2010 US NHANES,” *International Journal of Environmental Research and Public Health* 17, no. 5: 1552, 2020, <https://doi.org/10.3390/ijerph17051552>

13 Katrina Smith Korfmacher, Emily A. Benfer, and Matthew Chachère, “Lead Laws and Environmental Justice in New York,” *NYSBA The Environmental Lawyer* 39, no. 1 (Fall/Winter 2019): 50.

14 Robert Sampson & Alix Winter, “The Racial Ecology of Lead Poisoning: Toxic Inequality in Chicago Neighborhoods, 1995-2013,” *Du Bois Review: Social Science Research on Race*, 13, no.2 (2016): 261-283. doi:10.1017/S1742058X16000151

15 For an in-depth examination of racial discrimination and segregation in US housing policy see: Richard Rothstein, *The Color of Law: A Forgotten History of How Our Government Segregated America*, New York; London: Liveright Publishing Corporation, a division of W.N. Norton & Company, 2017

16 Ben Knight, “Lead Poisoning Reveals Environmental Racism in the U.S.,” *EcoWatch*, May 7, 2020, <https://www.ecowatch.com/lead-environmental-racism-2645941587.html>

17 Maria Godoy, “In U.S. Cities, The Health Effects of Past Housing Discrimination Are Plain To See,” *NPR*, November 19, 2020, <https://www.npr.org/sections/health-shots/2020/11/19/911909187/in-u-s-cities-the-health-effects-of-past-housing-discrimination-are-plain-to-see>

Buffalo,¹⁸ 35% in Utica,¹⁹ and 26.5% in Syracuse.²⁰ Furthermore, housing discrimination in the private market persists today, as thoroughly examined by Newsday's three-year investigative reporting into egregious racial discrimination by Long Island realtors.²¹



State Senator Cordell Cleare Stands with Lead Free Kids New York - Albany, NY March 31, 2022

Why Community Foundations?

Given these geographic disparities in rates of childhood lead poisoning—which are strongly correlated to race—place-based funders are well suited for grantmaking and deep engagement where childhood lead poisoning is most pronounced. In New York State, several community foundations have stepped up on lead poisoning issues in their region. In Western New York, the Community Foundation for Greater Buffalo has led and funded efforts including the Get Ahead of Lead²² campaign, the Green & Healthy Homes Initiative,²³ the development of a community Lead Action Plan,²⁴ and convening the Buffalo & Erie County Lead Safe Taskforce. The Central New York Community Foundation has similarly supported the Green and Healthy Homes Initiative in Syracuse. And the foundation convenes the Lead Safe CNY initiative with over \$2 million in grant support.²⁵ In the Mohawk Valley, the Community Foundation of Herkimer and Oneida Counties has pledged \$5 million²⁶ to support the work of Lead-Free MV, a



18 Ben Knight, "Lead Poisoning Reveals Environmental Racism in the U.S.," *EcoWatch*, May 7, 2020, <https://www.ecowatch.com/lead-environmental-racism-2645941587.html>

19 Katrina Gerry, "Local Officials Are Worried About Increased Lead Exposure in Home Due to COVID Lockdowns," *CNY Homepage*, March 3, 2021, <https://www.cnyhomepage.com/news/local-news/796313/>

20 "Lead Exposure in Syracuse," Lead Safe CNY, <https://www.leadsafecny.org/lead-in-cny.html>.

21 Ann Choi, Keith Herbert, Olivia Winslow, and Arthur Browne, "Long Island Divided," *Newsday*, Nov 17, 2019, <https://projects.newsday.com/long-island/real-estate-agents-investigation/>

22 "Get Ahead of Lead," *Community Foundation for Greater Buffalo*, <https://www.cfgb.org/community-change/initiatives/get-ahead-of-lead/>

23 "Green & Healthy Homes Initiative," *Community Foundation for Greater Buffalo*, <https://www.cfgb.org/community-change/initiatives/ghhi/>

24 Kent Gardner, "Renewing Our Pledge: A Path to Ending Lead Poisoning of Buffalo's Most Vulnerable Citizens," Rochester: *CGR*, 2017, <https://cfgb.org/wp-content/uploads/2018/07/buffalo-lead-action-plan-final-report.pdf>

25 "Community foundation Commits More than \$2 Million to End Childhood Lead Poisoning in Syracuse," *Lead Safe CNY*, <https://www.leadsafecny.org/news/community-foundation-commits-more-than-2-million-to-end-childhood-lead-poisoning-in-syracuse>

26 "Community Foundation Announces \$5 Million Investment in Lead-Free MV Initiative," *Community Foundation of Herkimer and Oneida Counties*, <https://foundationhoc.org/news/community-foundation-announces-5-million-investment-in-lead-free-mv-initiative>.



nonprofit coalition convened by the HomeOwnershipCenter in Utica.²⁷ In New York City, The New York Community Trust has funded lead poisoning prevention advocacy at the local, national, and international levels, including Earthjustice's national litigation and advocacy²⁸ to phase out the use of leaded aviation fuel, or avgas, and other consumer products such as hair dye;²⁹ and the Lead Legal Strategies Partnership which provides technical assistance to 13 communities across the nation to improve laws to prevent lead exposure.³⁰



What Was Observed?

While Community Foundations are well-positioned to help fund direct-service programming and strategic planning for their communities, all communities must work within the limitations set by current state and federal health, housing, and environmental policy. As each foundation's independent grantmaking progressed, it became apparent that two challenges appeared universal:

- 1) A Programmatic Challenge: The reduction in childhood lead poisoning resulting from direct-service grantmaking is limited by the broader policy systems in which those direct-service programs must operate.
- 2) A Funding Challenge: Addressing the broader policy system at a statewide level is far too great a challenge and far too costly for any one community to "go it alone" and requires the collaboration and coordination of several advocacy organizations and funders.



Engage New York and Neighborhoods First Fund
Grantee Panel on Housing - Ford Foundation 2019

²⁷ Lead-Free MV, <https://www.leadfreemv.org>

²⁸ Irfan Hasan, "Grantmaker Profiles: The New York Community Trust," *Grantmakers in Health*, March 1, 2019, <https://www.gih.org/grantmaker-focus/the-new-york-community-trust/>

²⁹ "Lead in Hair Dye is Banned," *The New York Community Trust*, January 31, 2019, <https://www.nycommunitytrust.org/newsroom/lead-in-hair-dye-is-banned/>

³⁰ "Lead Legal Strategies Partnership," *National Center for Healthy Housing*, <https://nchh.org/tools-and-data/technical-assistance/lead-legal-strategies-partnership/>

Solving the Programmatic Challenge of Lead Poisoning Prevention

Programmatic Preparations for the Aligned Funding Model Lead Poisoning Prevention Statewide Advocacy Network

Beginning in July 2017, the Lead-Free Mohawk Valley Coalition (Lead-Free MV) staff in Utica, NY, convened bi-monthly conference calls for agencies and organizations working on childhood lead poisoning prevention issues in their community. The group became known as the New York State Lead Poisoning Prevention Statewide Advocacy Network (LPPSAN).

The calls fostered a learning community to share information and explore what state policy challenges the communities had in common. Over the next two and a half years, the network built relationships across the state. The group began with 20 representatives spanning Buffalo, Rochester, Syracuse, Utica, the North Country, and Albany. It peaked at 52 representatives across 35 organizations spanning Buffalo, Rochester, the


Finger Lakes, Syracuse, Utica, Albany/Capital Region, and New York City. Sector representation spanned: funders, academia, public interest lawyers, environmental justice groups, government advocacy organizations, healthcare providers, community and grassroots coalitions, county health departments, and housing rehabilitation organizations. LPPSAN members identified programmatic and policy challenges, including non-current EBLL data, the legal and technical limitations of the Lead-Web blood lead level data system, the lack of a housing registry or publicly shared environmental data, the lack of RRP enforcement, and the lack of universal primary prevention, among others.

In May of 2018, LPPSAN convened in Utica, and attendees were asked, “what do we want to accomplish in the next 2-3 years in the area of childhood lead poisoning policy and advocacy?” Using consensus-based facilitation methods, Amy Murphy of Murphy Consulting helped the network identify its strategic priorities:

1. Develop a Governance Framework for a Statewide Coalition
2. Change State Laws to Promote Primary Prevention
3. Promote Unification of Public Health Law & Building Codes
4. Build Public Will for Policy Change
5. Funding
 - a. Generate Sustainable Funding (creating new public revenue)
 - b. Advocate for Funding Priorities
6. Instigate Inter-Agency Task Force
7. Integrate Siloed Property Data
8. Increase Blood Lead Testing Compliance to Connect Children to Services

The recommendations from LPP SAN members would serve as the programmatic scope for an aligned fund.³¹

31 See Appendix for the strategic priorities identified by the Utica Convening attendees



The Programmatic Challenge

Limits to Direct-Service Grantmaking Outcomes: Why Policy & Advocacy Grantmaking with Funds Earmarked For Lobbying Is Needed

If the reduction in childhood lead poisoning resulting from direct-services grantmaking is limited by the broader policy systems in which those direct-service programs must operate, then grantmaking focused exclusively on a local direct-service framework to address childhood lead poisoning will have a limited impact. These limits are unlikely to be overcome without also addressing the following structural barriers to ending lead poisoning that emanate from state policy:

PUBLICLY AVAILABLE ELEVATED BLOOD LEAD LEVEL (EBLL) DATA IS NOT CURRENT NOR SUFFICIENTLY DISAGGREGATED

In November of 2021, the most current, publicly available Elevated Blood Lead Level (EBLL) data was from 2014,³² and the most current mapped data was from 2012.³³ Furthermore, EBLL data is not available in a sufficiently geo-targeted format. Data granularity is frequently presented at the county or zip code level of aggregation,³⁴ when health disparities are often most pronounced at the census tract or block group level. Tracking at a county or zip code level prevents

public awareness of the geographic clusters of lead poisoning risk that would be much more apparent at a census tract level.

NEW YORK'S LEGAL AND TECHNOLOGICAL LIMITATIONS OF THE LEADWEB SYSTEM MAKES IT NEARLY IMPOSSIBLE TO ALIGN STATE AND FEDERAL LEAD POLICY AND REGULATION

Legal Limitations

Given the current structure of New York State's Public Health Law, it is nearly impossible for local health departments to create HIPAA Business Associate Agreements (BAAs) or other similar contractual EBLL data sharing arrangements as required or encouraged by various Federal regulations and programs. The inability to create these legal agreements makes it much more difficult for HUD Lead Hazard Control Grant recipients that are not local health departments to prioritize households approved for lead hazard control by children's EBLLs as is required by HUD. It is also challenging for public/municipal housing authorities and municipal Housing Choice Voucher (HCV) program administrators to ensure compliance with HUD's Lead Safe Housing Rule (LSHR).

The LSHR requires housing authorities and HCV administrators to conduct lead risk assessments in their federally supported housing whenever they know a child with an EBLL resides there. When the HUD regulations were enacted, HUD envisioned that local health departments would enter into EBLL data-sharing agreements with municipal HCV program administrators and municipal/public housing authorities. After identifying a lead-poisoned child in federally supported housing,

32 "Childhood Blood Lead Testing and Elevated Incidence by Zip Code: Beginning 2000," New York State Department of Health, accessed August 24, 2021, <https://health.data.ny.gov/Health/Childhood-Blood-Lead-Testing-and-Elevated-Incidenc/d54z-enu8>

33 "Childhood Blood Lead Testing and Incidence of Blood Lead Levels of 10 µg/dL or Greater by County Map," New York State Department of Health, accessed August 24, 2021, <https://health.data.ny.gov/Health/Childhood-Blood-Lead-Testing-and-Incidence-of-Blood/iebf-7vjk>

34 "Childhood Blood Lead Testing and Elevated Incidence by Zip Code: Beginning 2000," New York State Department of Health, accessed August 24, 2021, <https://health.data.ny.gov/Health/Childhood-Blood-Lead-Testing-and-Elevated-Incidenc/d54z-enu8>

this regulatory construct would enable the local health departments to make a referral for an environmental investigation to the relevant housing agency or administrator and, in the case of the HCV program administrator, enforcement actions against the property owner to compel remediation if necessary. This model would help align state and federal regulations and programs for more cost-effective deployment of public resources while also providing communities with more options for enforcement mechanisms when required. LSHR is similar to the local health department's responsibility under New York State's Public Health Law to conduct environmental investigations, including lead risk assessments, when a child has an EBLL. Without this state and federal coordination, duplicative lead risk assessments will likely be conducted on the same property, increasing time and cost without protecting any additional children.

These challenges exist because New York State's Public Health Law limits the use of LeadWeb Data in Section 1370-a of the Lead Law:

The department shall: establish a statewide registry of lead levels of children provided such information is maintained as confidential except for (i) disclosure for medical treatment purposes, (ii) disclosure of non-identifying epidemiological data; and (iii) disclosure of information from such registry to the statewide immunization information system established by section twenty-one hundred sixty-eight of this chapter.³⁵

Since none of the federal regulations or programs fit

within these disclosure categories, New Yorkers cannot use these mechanisms in a coordinated way for their maximum impact of protecting our most vulnerable residents, our children. And as addressed earlier, the societal costs in New York State for one birth year cohort of lead-poisoned children in housing choice voucher supported housing is \$106,835,594.44,³⁶ to say nothing of the pain and suffering experienced by children and their families.

Technical Limitations

In addition to the above-mentioned statutory limitations on the use of LeadWeb data, a 2019 Report by the Office of the New York State Comptroller found several data systems limitations of the LeadWeb System. LeadWeb serves as the singular system of record for EBLL case coordination, but the Comptroller's office "... found significant issues with the reliability of the system's data."³⁷ The Comptroller's office found discrepancies between data managed in LeadWeb and the data used by local health departments. Some local health departments prefer to use the New York State Immunization Information System (NYIIS) as a workaround to access LeadWeb report data in a more user-friendly way.³⁸

LeadWeb is undergoing a series of IT enhancements to address some of these issues and modify the system to reflect the April 12, 2019, public health law amendment requiring the statutory definition of elevated blood lead level to be lowered to at least 5 µg/dL.³⁹ It should be noted that this amendment has increased the number of cases needing follow-up services from 24,989 under the 10µg/dL standard to 80,946 under the 5 µg/dL

35 New York State Public Health Law, Title 10, Article 13, §1370-a.2.(c)

36 Emily Benfer et al., "The Cost of Childhood Lead Poisoning in New York," Columbia Law School Health Justice Advocacy Clinic, 2019, https://web.law.columbia.edu/sites/default/files/microsites/clinics/health-advocacy/new_york_cba_1_1.pdf

37 "Department of Health: Lead Poisoning Prevention Program," *Office of the New York State Comptroller, Division of State Government Accountability*, Report 2018-S-12, August 2018, 12.

38 "Department of Health: Lead Poisoning Prevention Program," *Office of the New York State Comptroller, Division of State Government Accountability*, Report 2018-S-12, August 2018, 13.

39 This brought New York State into alignment with CDC's 2012 recommendation that 5µg/dL be used as a reference level of lead toxicity following the medical determination that there is no safe level of lead for children

standard.⁴⁰ With lead poisoning cases slightly more than tripling, there needs to be a timely implementation of the necessary IT upgrades, program and process redesign, and state funding for local health departments to ensure that all of New York's children receive the services to which they are legally entitled.

ENVIRONMENTAL DATA IS NOT SHARED WITH THE PUBLIC

Results of publicly funded lead risk assessments, let alone private sector lead risk assessments, in rental housing are not available in a publicly accessible housing registry such as Maryland's Lead Safe Rental Registry.⁴¹ Without a universal lead testing requirement for residential property and without a method for the public to access this environmental data, renters and homebuyers must rely exclusively on landlords and sellers to adequately disclose known lead hazards under the joint HUD/EPA lead-based paint disclosure rule.⁴²

Unlike EBLL information, lead risk assessment data for residential properties do not include protected health information. Therefore, the risk assessment data could be made available in much the same way that building code violations or restaurant health code violations are publicly available, especially for lead risk assessments paid for by the taxpayer. If this information were available in a publicly assessable and user-friendly way, then parents could make more informed choices about where to live without exposing their children to a neurotoxin.

It should also be noted that lead in public school drinking water data is publicly available, although not user-friendly, per its enabling legislation. New York League of Conservation Voters has produced a report to make this data more accessible and understandable for the public.⁴³

LACK OF RENOVATION, REPAIR, AND PAINTING (RRP) ENFORCEMENT BY THE US EPA AND NEW YORK STATE

For much of New York State, there is insufficient EPA staffing to enforce RRP regulations adequately. EPA Region 2 has 3.5 full-time inspectors working on RRP Enforcement for all of New York State.⁴⁴ One of the most significant contributors to creating lead dust hazards (which cause up to 40% of lead poisoning cases) is home renovations that are not conducted in a lead-safe manner.⁴⁵ Given the estimated 629,865 homes with potential lead hazards and children under age six, each EPA inspector is responsible for a potential complaint-based inspection pool of up to 179,961 households in New York State. The agency receives about 300 tips, complaints, and referrals from New York State annually. In 2018 and 2019, these inspections resulted in only seven RRP enforcement actions each year.⁴⁶ The state may directly administer the RRP program, subject to federal approval, and the Governor may take this action without legislative involvement. Still, New York has repeatedly declined to do so since RRP regulations took effect in 2008 and were amended in 2010 and 2011.

40 "Department of Health: Lead Poisoning Prevention Program," *Office of the New York State Comptroller, Division of State Government Accountability*, Report 2018-S-12, August 2018, 14-15. <https://www.osc.state.ny.us/files/state-agencies/audits/pdf/sga-2019-18s12.pdf>

41 "Facts about Maryland's 'Lead Law': Summary of Compliance Requirements Residential Rental Properties," *Maryland Department of the Environment*, <https://mde.state.md.us/programs/Land/Documents/LeadFactSheets/LeadfsStandardOfCare.pdf>

42 "Lead-Based Paint Disclosure Rule," 24 CFR Part 35, Subpart A.

43 "5 is the New 15" *New York League of Conservation Voters*, 2021, <https://nylc.org/news/our-report-shows-we-need-a-stronger-lead-poisoning-prevention-law/>

44 Alice Kreher, "Lead-Safe Renovation, Repair, and Painting Activities in New York State: Analysis of the Proposal for State Management of the RRP Rule," *Buffalo: ILR Buffalo Co-Lab & Community Foundation for Greater Buffalo*, February 2020, 10. https://ppgbuffalo.org/files/documents/lead_rrp_activities_in_nys.pdf

45 Alice Kreher, "Lead-Safe Renovation, Repair, and Painting Activities in New York State: Analysis of the Proposal for State Management of the RRP Rule," *Buffalo: ILR Buffalo Co-Lab & Community Foundation for Greater Buffalo*, February 2020, 7. https://ppgbuffalo.org/files/documents/lead_rrp_activities_in_nys.pdf

46 Alice Kreher, "Lead-Safe Renovation, Repair, and Painting Activities in New York State: Analysis of the Proposal for State Management of the RRP Rule," *Buffalo: ILR Buffalo Co-Lab & Community Foundation for Greater Buffalo*, February 2020, 10. https://ppgbuffalo.org/files/documents/lead_rrp_activities_in_nys.pdf

LACK OF UNIVERSAL PRIMARY PREVENTION

With secondary prevention—taking public health action after a child’s lead exposure—being the only universal lead poisoning prevention program in the state, we use children as lead detectors when the health effects of lead exposure are irreversible. Whereas primary prevention—taking public health action to prevent a child’s exposure to lead—funding and legal enforcement constructs are only available in a limited number of cities in New York State and, as of 2021, are administered by a total of 15 of New York’s 58 local health departments.⁴⁷

The Programmatic Solution

Support Statewide Advocacy Campaigns That Address These and Other Structural Barriers to Eliminating Childhood Lead Poisoning

For the two and a half years that the Lead Poisoning Prevention Statewide Advocacy Network met, it functioned mainly as a learning community. At times, the network coordinated a responsive strategy to the Governor’s or Legislature’s proposed policy changes, coordinating responses to combat counterproductive policy proposals and lend support to any beneficial policies. By learning about these and other structural barriers in greater depth, the community foundations recognized they needed to support coalition building

and statewide advocacy campaigns to proactively, rather than reactively, address structural issues. Furthermore, the public benefit of statewide policy change would extend far beyond the communities of Buffalo, Syracuse, Utica, and New York City to the entire state, as all of New York’s communities face these structural challenges, and all nonprofit organizations must work within this system. The funders also recognized that no one community could “go it alone” to achieve these policy changes. Instead, it is necessary to engage in coalition building to harness the collective power of local service providers, grassroots organizations, impacted and affected individuals, public and environmental health experts, environmental justice organizations, policy and advocacy organizations, et cetera.



⁴⁷ “New York State Childhood Lead Poisoning Prevention Program (NYS CLPPPP),” *National Center for Healthy Housing*, <https://nchh.org/tools-and-data/technical-assistance/nys-clpppp/>

Solving the Funding Challenge of Lead Poisoning Prevention Policy & Advocacy Work

Foundation Preparations for an Aligned Funding Model

Much like the need for coalition-building among advocacy groups, nonprofits, etc., given the immense scope and scale of the problem, the funders also participated in two key funder collaboratives that enabled the development of the aligned funding model.

Engage New York (ENY) – a network of foundation leaders from across New York that envisions a state where the assets of philanthropy and communities work together to transform unjust systems and have a meaningful impact for all New Yorkers.⁴⁸ At the time of LPPSAN’s launch, Engage New York was promoting learning and funding around four critical areas of systems change: immigration reform, criminal justice



reform, complete count for the 2020 census, and healthy & affordable housing. Cara Mattaliano, Senior Director of Policy & Partnerships at the Community Foundation for Greater Buffalo, served as co-chair of Engage New York and secured a portion of Engage New York Program Director Lisa Fasolo Frishman’s time to support the work of LPPSAN. This essential partnership provided needed capacity to the LPPSAN learning community while the funders explored collaborative funding models to advance LPPSAN’s policy ideas.

Lead Funders Action Network (LFAN) – Founded in April 2018 by the JPB Foundation, Robert Wood Johnson Foundation, and Joyce Foundation. LFAN brings together national, regional, state, and local foundations to work collaboratively and strategically to address gaps in the field of childhood lead poisoning and make philanthropic investments more synergistic to advance the prevention of the disease.⁴⁹ The funders attended the inaugural meeting of LFAN, which occurred one month before the May 2018 LPPSAN convening in Utica. LFAN, which is now part of the Health and Environmental Funder’s Network (HEFN), has helped coordinate field-building grants, which have included investments in guiding equitable policymaking, better lead policy, innovative lead remediation financing models, models for pooled and aligned funding, a technical assistance program for local policy change, grantee toolkits for obtaining lead remediation funding, and a cost-benefit calculator for all 50 states.⁵⁰

48 Engage New York: Grantmakers for Community Engagement, <https://www.engagenewyork.org>

49 "Lead Funders Action Network," *Health and Environmental Funders Network*, https://www.hefn.org/lead_funders_action_network_0

50 For additional information on past LFAN-driven grants, see: https://www.hefn.org/lead_funders_action_network_0



Engage New York and Neighborhoods First Fund's Funder Breakout on Housing Policy - Ford Foundation 2019

Through their grantmaking strategies and joint participation in LFAN and ENY, the community foundations explored their shared goals at the nexus of lead poisoning prevention and policy & advocacy grantmaking. By 2019, the four foundations agreed to align grant resources for at least two years to jointly support a statewide coalition to advance lead poisoning prevention policy solutions.

The Funding Challenge Limitations to Isolated Grantmaking: Why Multi-Funder Alignment is Needed

The next challenge was marshaling the needed resources to advance the coalition-building and advocacy campaign strategy. In general, there are limited philanthropic resources for healthy housing & environmental health advocacy in New York State, and even more significant limitations on funding for lobbying. Many funders focused on advocacy grantmaking do not focus on healthy housing or environmental health policy. Many funders focused on healthy housing, or environmental health grantmaking do not focus on legislative

advocacy. A well-thought-out mechanism to pool, align or otherwise coordinate investments among the limited number of funders working at the nexus of advocacy and childhood lead poisoning prevention grantmaking was needed.

A 2018 Stanford Social Innovation Review journal article examined advocacy grantmaking and found in 2014, just slightly more than 4 percent of total giving was for policy & advocacy grantmaking. Though current levels of advocacy grantmaking are low, there is interest in philanthropy for more as the Center for Effectively philanthropy found that more than 40 percent of Foundation CEOs intend[ed] to increase advocacy grantmaking at the state and local level.⁵¹ Another more recent Center for Effective Philanthropy survey found that 25 percent of nonprofit leaders ask for increased funding for advocacy work, including flexible or non-restricted grants and long-term grants, given the complexity and long-term nature of most public policy advocacy efforts.⁵²

While there is a general lack of funds for policy & advocacy grantmaking, resources are even more scarce for lobbying activities. Private foundations are prohibited from earmarking grants for lobbying activities which curtails a large segment of the philanthropic community. That said, grantees of private foundations receiving general

51 In 2014 policy & advocacy grantmaking totaled \$2.6 billion out of the \$60.2 billion in grantmaking that year or approximately four percent. Patrick Guerriero & Susan Wolf Dittkoff, "When Philanthropy Meets Advocacy," *Stanford Social Innovation Review*, Summer 2018: 50. https://ssir.org/articles/entry/when_philanthropy_meets_advocacy#

52 Naomi Orensten, Ellie Buteau, Hannah Martin, Kate Gehling, "Policy Influence: What Foundations are Doing and Why," *Center for Effective Philanthropy*, 2020: 17. http://cep.org/wp-content/uploads/2020/06/CEP_PublicPolicy.pdf

LPPSAN Members at the Utica
Convening - May 9, 2018



operating support grants may use them to support lobbying activities if the grantee so chooses. Private Foundations may also fund the non-lobbying portions of an advocacy campaign using the project grant rule.⁵³ Options for public charities, such as community foundations, are more expansive, including the ability to earmark grant funds for lobbying, provided it does not become a “substantial” amount of the foundation’s work. Given the imprecise definition of substantial lobbying activities, public charities have the option to take the 501(h) election, so named after the section of the Internal Revenue Code, which allows the foundation to engage in limited lobbying and lobbying earmarks in grants up to certain dollar limits. While the 501(h) election is available to all 501(c)(3)

organizations, only 38 percent of community foundations have taken the election.⁵⁴

A final challenge to marshaling sufficient resources is the widespread practice of foundations having overly restrictive prohibitions for lobbying in their “boilerplate” language for grant agreements. Center for Effective Philanthropy (CEP) research has found nonprofit leaders requesting that foundations remove overbroad lobbying prohibitions from their grant agreements or contracts. CEP also found that only 27 percent of foundations say general operating support is extremely important to them, and 54 percent have grant agreement templates that prohibit lobbying activities.⁵⁵

53 For more on the project grant rule and general operating support grants see: “Private and Public Foundations May Fund Charities that Lobby,” *Bolder Advocacy*, https://bolderadvocacy.org/wp-content/uploads/2012/04/Private_and_Public_Foundations_May_Fund_Charities_that_Lobby.pdf

54 Naomi Orensten, Ellie Buteau, Hannah Martin, Kate Gehling, “Policy Influence: What Foundations are Doing and Why,” *Center for Effective Philanthropy*, 2020: 50. http://cep.org/wp-content/uploads/2020/06/CEP_PublicPolicy.pdf

55 Naomi Orensten, Ellie Buteau, Hannah Martin, Kate Gehling, “Policy Influence: What Foundations are Doing and Why,” *Center for Effective Philanthropy*, 2020: 17. http://cep.org/wp-content/uploads/2020/06/CEP_PublicPolicy.pdf

The Funding Solution Aligned Grantmaking Across a Network of Funders Can Alleviate the Lack of Policy & Advocacy Funding with Lobbying Earmarks

Aligning funding across a network of funders increases the total grant award to an impactful amount. Consolidating application and reporting requirements across several foundations into one streamlined process also reduces grantee time spent on applications and reporting, thereby increasing the time available for their charitable activities. Furthermore, public charities, such as community foundations, are uniquely positioned to support advocacy, including lobbying. Given their diversity of funding sources and board membership, public charities may earmark a portion of a grant for lobbying so long as the dollar amount is within limits set by the 501(h) election.⁵⁶ With all the reasons to move forward, some funders in the group had limited experience with advocacy grantmaking, especially earmarking grants for lobbying, and other funders had limited experience with collaborative grantmaking. Given the differences in experience, this effort served as an experiment in both advocacy grantmaking and aligned grantmaking.

The foundations initially pursued a pooled funding model, but several logistical challenges were inherent in pooling resources at one foundation. Arturo Garcia-Costas, Program Officer, Local, National, and International Environment at the New York Community Trust, suggested an aligned funding model would be

the fastest way to utilize each foundation's existing grantmaking process and procedures but with a shared commitment to use a single application and grant report. The streamlined application and reporting process was intended to reduce the administrative burden on potential grant seekers by having only one application and grant report rather than four separate applications and reports.

This aligned funding model benefited from recent information technology investments made by the New York Community Trust for its grant portal. The Trust's electronic application system was designed to incorporate third-party reviewers for grant applications which greatly simplified the administrative work needed to coordinate grant review, scoring, and selection.

For funders where this was their first grant with a lobbying earmark, a few internal process and procedure changes were required to track and disclose the lobbying earmark properly. Foundations are required to disclose direct and grassroots lobbying expenditures (including grant earmarks) on Schedule C of the annual IRS 990 filing, which was easy to do given the Trust's grant application portal and budget templates. The internal process changes made by foundations newer to this type of grantmaking included: filing the 501(h) election with the IRS, working with the foundation's accounting department to ensure lobbying earmarks in grants are appropriately tracked and disclosed, informing the auditor of the foundation's new use of lobbying earmarks, reviewing the grant agreement to ensure there are no prohibitions on lobbying, and keeping the foundation's board informed of the process changes especially the grantmaking and audit committees.

⁵⁶ "Taking the 501(h) election," *National Council of Nonprofits*, <https://www.councilofnonprofits.org/taking-the-501h-election>



Lead-Free Kids New York Impact to Date

ADVOCACY

- Secured the first legislative hearing on childhood lead poisoning in over 25 years
 - Joint Senate Health & Housing Committee Hearing held on November 30, 2021
- 100+ meetings with legislators
- 4 Virtual Advocacy Days
- 1 “Dear Colleague” Letter Sent

COALITION BUILDING

- Launched and grew Coalition to 34 member organizations
- Created an informational network for 13 organizations to support and inform the Coalition’s work
- Co-hosted Lead Poisoning Prevention Awareness Week press conferences with local Coalition members in Albany, Buffalo, Jamestown, Syracuse, and Utica

COMMUNICATIONS

- Six social media toolkits disseminated
- 275+ social media posts
- Four earned media stories published
- One Op-ed published
- Launched the Coalition website: Leadfreekidsny.org

LEGISLATION

- 5 Bills Introduced:
 - Safe School Drinking Water - S.2122/A.160
 - Lead Testing at the Point of Sale – S.2142/A.6608
 - Restoration of Property Insurance Coverage – S.3079/A.7488
 - Lead-Safe Renovation, Repair and Painting Act – S.3079/A.7488
 - Childhood Lead Poisoning Prevention and Safe Housing Act of 2022 – S.8453
- 2 Passed Bills Assembly:
 - Restoration of Property Insurance Coverage for Exposure to Lead-based Paint: Passed Assembly on March 24, 2022
 - Lead Testing at the Point of Sale: Passed Assembly on June 9, 2021
- 1 Bill Signed into Law:
 - Safe School Drinking Water Act Signed: December 22, 2021

Timeline

- JULY 2017**
Lead Poisoning Prevention Statewide Advocacy Network (LPPSAN) launched
- JANUARY 2018**
Engage New York supports LPPSAN as part of its Safe & Healthy Housing issue area.
- APRIL 2018**
Lead Funders Action Network (LFAN) founded
- MAY 2018**
LPPSAN holds Utica Convening to establish a policy agenda
- AUGUST 2019**
Community Foundations meet at Ford Foundation to design an aligned funding model
- NOVEMBER 2019**
Request for proposals issued by New York Community Trust for aligned funding
- JUNE 2020**
Lead Free-Kids New York Coalition awarded aligned funding; LPPSAN dissolved
- OCTOBER 2020**
Official launch of the Lead-Free Kids New York Coalition
- JUNE 2021**
Safe School Drinking Water Act passes New York State Senate and Assembly
- JUNE 2021**
Lead Testing at the Point-of-Sale passes the Assembly
- NOVEMBER 2021**
Lead-Free Kids New York secures the first legislative hearing on lead poisoning prevention in over 25 Years
- DECEMBER 2021**
Safe School Drinking Water Act Signed into Law by Governor Hochul
- MARCH 2022**
Restoration of Property Insurance Coverage for Exposure to Lead-based Paint Passes Assembly
- OCTOBER 2022**
Lead-Free Kids New York cohosts press events with its local Coalition members in Albany, Buffalo, Jamestown, Syracuse, and Utica during Lead Poisoning Prevention Awareness Week
- DECEMBER 2022**
The Coalition launches the leadfreekidsny.org website

Conclusion

Issues stemming from systemic inequity, such as childhood lead poisoning, cannot be solved through direct-service programming alone. Systems change requires the alignment of the public, private, and social sectors around a common goal and must often include changes to public policy and public funding. Parallel efforts to 1) build a coalition of grassroots advocacy organizations and 2) align grantmaking across a coalition of funders, are needed to commit the level of resources required over the long term to achieve systems change.

Through this model of parallel coalition building and funder alignment, the four community foundations

were able to align \$350,000 in grantmaking for the 2021-2022 legislative session and \$355,000 in renewal grantmaking for the upcoming 2023-2024 legislative session. While this core funding has helped launch the Lead-Free Kids New York Coalition, there remains a role for additional funders, especially private foundations, to join this effort by supporting the Coalition's outreach and education work. This work includes but is not limited to communications and message testing, budget and fiscal impact modeling, capacity-building efforts with grassroots partners, data visualization, and mapping. For more information on the aligned funding model or how to join this collaboration, please email Engage New York Project Consultant John Monaghan at John@MonaghanConsulting.com or Engage New York Program Director Lisa Fasolo Frishman at lfasolofrishman@gmail.com.

State Senator Sean Ryan, Assemblymember Jonathan Rivera, and State Senator Cordell Cleare show support for Lead Free Kids New York - Albany, NY March 31, 2022



Appendix: Strategic Priorities from Utica Convening

New York State Lead Poisoning Prevention Statewide Advocacy Network								
STRATEGIC FRAMEWORK What do we want to accomplish in the next 2-3 years in the area of policy and advocacy?								
Develop Governance Framework for State-wide Coalition	Change State Laws to Promote Primary Prevention	Promote Unification of Public Health Law & Building Codes	Build Public Will for Policy Change	Funding		Instigate Inter-Agency Task Force	Integrate Siloed Property Data	Increase Testing Compliance to Connect Children to Services
				Generate Sustainable Funding	Advocate for Funding Priorities			
Coalition prioritization process	Comprehensive primary prevention statewide	Connect building/sanitary codes to address lead	Change the narrative	Sustainable funding system	State remediation Funding for RRP	Reenergize & hold accountable the Inter-Agency Task Force	NYS shared database	Require proof of lead test for school admissions
Develop a system for prioritizing actions based on values and principles	Develop strategic housing plan	Enforce existing housing regulations	Large scale statewide media campaign	o Tax credits o Paint tax o Paint surcharge	Funding for: o Abatement o Remediation o Demolition	Implement Inter-Agency Task Force recommendations	Portal for everything	Integrate lead into school health & education information
Analyze gaps in existing NYS policies	Align federal & state policies & requirements	Code authority to cite lead	NYS PSAs	Clean housing fund	Window replacement initiative	Promote effective interagency coordination		Blood lead levels
Network legislative policy agenda	Advocate for statewide RRP	Add code violations to tax roll	Public awareness & education	Quantify savings to Medicaid, State education	Window & door replacement for pre-1978 housing & porches	Integrate lead into all home visits		
Durable network	o NYS enforcement o Certification for all contractors o Effective RRP code enforcement	Fill in enforcement gaps	Art collaboration for community leadership	Use RRP training costs to fund lead	Lower NYS BLL response & fund increase in workload			
	Establish a "floor" for state action level = federal level	Stiffer enforcement						
	Lower action level to 5 ug/dL (with funding)	NYS lead ordinance						
	Improve system for responding to EBLs	Statewide minimum lead ordinance						
	Lead testing for homes purchased (pre-1978)							
	Expand water testing for lead to childcare settings							
	Address aviation gas at airports							

