

RHODE ISLAND DEPARTMENT OF HEALTH

CHILDHOOD LEAD POISONING PREVENTION PROGRAM

**LEAD SCREENING AND  
CASE MANAGEMENT PLAN**  
March 2006



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# TABLE OF CONTENTS

|   |    |
|---|----|
| EXECUTIVE SUMMARY .....   | 4  |
| SECTION I. RHODE ISLAND'S CHILDHOOD LEAD POISONING PREVENTION ADVISORY COMMITTEE.....   | 5  |
| SECTION II. LEAD SCREENING .....  | 7  |
| 1. <i>Background</i> .....  | 7  |
| 2. <i>The RI Lead Screening Law</i> .....   | 7  |
| 3. <i>Guidelines for Lead Screening Requirements</i> .....  | 8  |
| 4. <i>Proposal to Clarify the Lead Screening Requirements</i> .....   | 8  |
| 5. <i>Current Lead Screening Activities and Quality Assurance Efforts</i> .....   | 12 |
| 6. <i>Evaluation and Outcome Measures of Lead Screening</i> .....   | 25 |
| 7. <i>An Outlook to the Future</i> .....  | 26 |
| SECTION III. CAPACITY TO ANALYZE BLOOD LEAD SCREENING AND ENVIRONMENTAL LEAD DUST CLEARANCE SAMPLES AND ELECTRONIC REPORTING..... | 28 |
| 1. <i>Background</i> .....  | 28 |
| 2. <i>Laboratory Capacity for Blood Lead Specimens and Environmental Sample Analysis</i> .....                                    | 28 |
| 3. <i>Analysis of Lead Clearance Samples</i> .....  | 29 |
| 4. <i>Electronic Reporting</i> .....  | 30 |
| 5. <i>An Outlook to the Future</i> .....  | 31 |
| SECTION IV. CASE MANAGEMENT .....   | 32 |
| 1. <i>Background</i> .....  | 32 |
| 2. <i>Current Activities and Intervention levels</i> .....  | 35 |
| 3. <i>Case Management Resources</i> .....   | 39 |
| 4. <i>Enforcement</i> .....   | 42 |
| 5. <i>Quality Assurance Activities</i> .....  | 43 |
| 6. <i>Evaluation and Outcome Measures</i> .....   | 44 |
| 7. <i>An Outlook to the Future</i> .....  | 45 |
| SECTION V. EDUCATIONAL STRATEGIES .....   | 46 |
| 1. <i>Lead Month</i> .....  | 46 |
| 2. <i>Outreach to providers</i> .....   | 46 |
| 3. <i>Outreach to Schools, Daycares, and Social Service Agencies</i> .....  | 46 |
| 4. <i>Mailings to families</i> .....  | 46 |
| 5. <i>"Keep It Clean" campaign</i> .....  | 47 |
| 6. <i>Parent Consultant</i> .....   | 47 |
| 7. <i>"Lead Update"</i> .....   | 47 |
| 8. <i>Web Page</i> .....  | 47 |
| 9. <i>Educational Materials</i> .....   | 47 |
| 10. <i>Toll free line: 1-800-942-7434</i> .....   | 47 |
| 11. <i>An Outlook to the Future</i> .....   | 48 |

|   |           |
|---|-----------|
| <b>SECTION VI. APPENDICES.....</b>  | <b>49</b> |
| APPENDIX 1 RHODE ISLAND CHILDHOOD LEAD POISONING PREVENTION ADVISORY<br>COMMITTEE .....     | 50        |
| APPENDIX 2 RHODE ISLAND LEAD SCREENING STRATEGIES .....                                     | 52        |
| APPENDIX 3 RHODE ISLAND EPSDT PERIODICITY SCHEDULE .....                                    | 54        |
| APPENDIX 4 MANAGED CARE ORGANIZATION MEMORANDUM OF<br>UNDERSTANDING.....                    | 58        |
| APPENDIX 5 PARENT REMINDER LETTER FOR UNSCREENED CHILD AT<br>15 MONTHS .....                | 69        |
| APPENDIX 6 LEAD SCREENING AND REFERRAL GUIDELINES FOR REFUGEE<br>CHILDREN .....             | 72        |
| APPENDIX 7 DISTRIBUTION OF RHODE ISLAND CHILDREN SCREENED ONCE<br>BY 18 MONTHS OF AGE ..... | 74        |
| APPENDIX 8 POLICY FOR LEAD SCREENING SPECIMEN ANALYSIS .....                                | 76        |
| APPENDIX 9 LEAD CENTER MEMORANDUM OF UNDERSTANDING.....                                     | 79        |
| APPENDIX 10 INTERVENTION OFFERED BY BLOOD LEAD LEVEL- FLOW CHART .....                      | 86        |
| APPENDIX 11 CASE MANAGEMENT EVALUATION.....   | 88        |

## EXECUTIVE SUMMARY

As we enter our fourth decade of public health efforts to prevent childhood lead poisoning, Rhode Island has an ultimate goal to eliminate lead poisoning by 2010, and must diligently work on making that goal a reality. As stated by the Centers for Disease Control and Prevention (CDC) in its statement from 1991, *"Elimination of childhood lead poisoning will require efforts from both the private and public sectors, will require a shift in emphasis to primary prevention, will take time and resources, should proceed in a rational manner, with the highest risk children being made the highest priority, and can be achieved"*.

With this tremendous challenge ahead of us, Rhode Island has made a shift to put significant resources in two areas of primary prevention: educational strategies and preventive efforts that can assist families to have a lead safe home for their families. While we are putting major emphasis in primary prevention efforts that will take us one step closer to elimination of childhood lead poisoning, we have to maintain our secondary prevention efforts, screening children for lead poisoning as the test is the only way to identify lead poisoning, ensuring they receive appropriate case management and continuing our enforcement efforts to improve housing units that have been occupied by lead poisoned children.

Maintaining screening rates in Rhode Island will require continued effort in three areas of public health practice: assessment, policy development and quality assurance. We will continue to use the principles of the Title V, Maternal and Child Health (MCH) Program: culturally competent, community based, comprehensive and coordinated care for all children and families, integrating into all levels of prevention programs information and services to address childhood lead poisoning. We will also continue to use KIDSNET, Rhode Island's child health information system <http://www.health.ri.gov/family/kidsnet/index.php> as a quality assurance tool and resource for providers to measure and enhance their lead screening performance. Maintaining case management for the families with significantly lead poisoned children, as well as enforcing the removal of lead hazards in the units that families have occupied, will continue to require resources and the continuity of the current infrastructure. We will continue to rely and foster relationships that can help us enhance our efforts in these areas as well.

The Rhode Island Childhood Lead Poisoning Prevention Program (RICLPPP) would like to sincerely thank all our partners who are involved in services provided to young children in Rhode Island. This document has been prepared with input from a variety of partners, including Medicaid and state Managed Care Organizations (MCO), Rhode Island Housing, the Housing Resources Commission (HRC), the state's Lead Centers and Lead Clinics, laboratories, Head Start agencies, and other programs based in the Rhode Island Department of Health's (DOH) Division of Family Health (DFH). These programs include KIDSNET, the Women, Infants and Children (WIC) Program, the Immunization Program, the Family Outreach Program (FOP), and many others who participate in the RICLPPP Advisory Committee.

The process of developing this document has given us all a chance to appreciate the power of our integrated approach to the prevention of childhood lead poisoning and to share with others some of the root causes for our nationally recognized success. We look forward to continuing to work with our partners on re-evaluating and improving both our primary and secondary prevention strategies in years to come.

## **SECTION I. Rhode Island's Childhood Lead Poisoning Prevention Advisory Committee**

The RICLPPP officially formed its Lead Screening Advisory Committee early in 1998 after the CDC issued the *Screening Young Children for Lead Poisoning: Guidance for State and Local Public Health Officials*. This guidance asked programs to develop a statewide screening plan with community stakeholders and encouraged statewide community participation to determine if the state needed universal or targeted screening. When it was initially formed, the mission of the Advisory Committee was to assist the RICLPPP in reviewing its statewide screening plan and enhancing lead screening rates. The committee assisted in and advised the RICLPPP on the development of a number of screening activities, including:

- Outreach conducted to parents of unscreened 18-month-old children, utilizing data from KIDSNET;
- Impact and evaluation of past summer screening efforts;
- Review of the Lead Screening and Referral Guidelines;
- Screening efforts in collaboration with the MCOs;
- Quality improvement efforts initiated in pediatric practices linked to KIDSNET
- Data sharing efforts to assess the proportion of children enrolled in Head Start Programs without evidence of lead screening;
- Providing Head Start Programs with the tools to better assess screening compliance in their enrolled population through access to KIDSNET;
- The establishment of "free" lead clinics for the uninsured children.

The RICLPPP completed its first Lead Screening Plan in October of 2000. After its submission, the RICLPPP continued working with the Advisory Committee to keep the members informed about the progress of its implementation and ongoing screening efforts.

Early in 2002, the RICLPPP decided that the Advisory Committee should be expanded and structured in such a way that participants could provide feedback on matters beyond lead screening. The first meeting of this expanded group was held in July of 2002. Since this expansion, the Advisory Committee has been included in discussions on environmental efforts, case management, outreach and education, and legislative initiatives. This expanded Advisory Committee has been a critical component of the RICLPPP's work in recent years. The Committee has been involved in the development of RICLPPP's Plan to Eliminate Childhood Lead Poisoning by 2010 and provided feedback on many drafts of this document throughout its development. Additionally, some members of the Advisory Committee have assisted on smaller committees to deal with specific issues, such as the Housing Data Work Group that was formed in the summer of 2005 to look at issues around housing data and potential sources of information the RICLPPP could utilize in evaluating its progress on the state elimination plan. Other topics that have been included at Advisory Committee meetings are new outreach and education initiatives, such as the nursing student-training program that the RICLPPP began in June 2005, as well as legislative updates on the Lead Hazard Mitigation Law.

The RICLPPP's Advisory Committee (appendix 1) is now a formal body of membership that reviews policies and initiatives including but not limited to, the lead screening and case

management plan. The Advisory Committee is convened quarterly and continues to expand in membership.

## SECTION II. LEAD SCREENING

*Screening is important both to ensure that poisoned children are identified and to generate data to target primary prevention activities<sup>1</sup>*

### 1. Background

As originally formulated in the 1991 Lead Poisoning Prevention Act and further refined in the Rhode Island Rules and Regulations for Lead Poisoning Prevention [http://www.rules.state.ri.us/rules/released/pdf/DOH/DOH\\_3357.pdf](http://www.rules.state.ri.us/rules/released/pdf/DOH/DOH_3357.pdf) effective 1993, Rhode Island mandates universal screening for lead poisoning, which requires that every child under six years of age be screened for lead poisoning at least once annually.

When blood lead levels are elevated, more frequent blood lead testing is required regardless of the age of the child. Additionally, in the cases developmentally delayed, symptomatic children or other special cases, a clinical judgment is advised and a different lead testing schedule may be recommended. For additional guidance and/or special circumstances, a consultation with RICLPPP's Medical Director, Peter R. Simon, MD, MPH, is available to health care professionals.

### 2. The RI Lead Screening Law

Chapter 24.6, the "Lead Poisoning Prevention Act" of the Rhode Island General Laws was passed in 1991. The law's Rules and Regulations were issued in 1992, calling for actual implementation at the beginning of 1993. Rhode Island is one of the few states (along with Massachusetts, New York, Illinois and Delaware) in the nation with screening legislation in place and was the second state to implement a screening law, following CDC recommendations issued in 1991. A united effort by legislators, public health officials, advocates and parents is to be commended for the realization of a task that has proven to be near to impossible in other states.

The law is a comprehensive compendium of requirements that aim for a safer environment for Rhode Island children. The law can be described as a broad umbrella of components that includes sections on lead screening, lead inspections, methods of measurement and standards, reporting requirements, real estate notification and disclosure, provisions for lead hazard reduction, licensing and certification requirements, compliance and enforcement.

With regard to lead screening, Rhode Island's lead poisoning prevention law plays a critical role in the surveillance of lead poisoning. It clearly outlines a lead screening schedule at appropriate ages and provides for the discontinuance of blood lead testing if certain conditions apply or if religious beliefs impede parents from completing the blood lead test. Furthermore, the law facilitates data collection through a centralized specimen analysis system, managed and administered by the Rhode Island State Laboratory. The screening recommendations combined with data collection and many other efforts on the part of health care providers and the RICLPPP over the last few years, has reached a 75% screening rate for a birth cohort of 18-month-old

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<sup>1</sup> "Preventing Lead Poisoning in Young Children", a statement by the Centers for Disease Control, October 1991, page 39.

children born in 2001, who are screened for lead at least once, where 52% are screened at least twice by 36 months of age at least 12 months apart.

The Rhode Island lead poisoning prevention law has been called one of the most comprehensive examples of lead screening legislation in the country, and continues to be used as a model for the formulation of lead screening policies in other states. The law has allowed the state to achieve:

- The highest rates of compliance with lead screening in the country,
- An electronic surveillance system that allows for continuous assessment and quantification of lead poisoning prevalence, and the ability to identify resources and refine further prevention strategies
- A foundation for quality improvement partnerships with primary care providers (PCP), MCOs and other key agencies.

The comprehensive and highly efficient report-generation capacity of Rhode Island's lead elimination surveillance system (LESS), provides a solid infrastructure to continue monitoring and building upon our secondary prevention services: "What gets measured, gets done".

### **3. Guidelines for Lead Screening Requirements**

Several lead screening tools and resources have been developed to assist health care professionals in understanding Rhode Island's lead screening requirements for children <http://www.health.ri.gov/lead/family/providers.php>.

The *Rhode Island Lead Screening and Referral Guidelines* were developed for pediatric health care providers. The guidelines provide a summary of the lead law and the required lead screening schedule, as well as guidelines for recommended actions and referrals. The guidelines are available in poster and pocket size.

*Best Practices for Lead Screening* were developed by soliciting recommendations from health care providers about actual practices used to ensure lead screening of children in their care.

The *Guidelines for the Collection, Submission and Transport of Capillary Blood Lead Screening Specimens* were developed as a resource for providers who choose to offer on-site capillary testing for children in their practice.

*Frequently Asked Questions and Answers about Lead Screening Requirements for Child Daycare, Preschools and Schools* were developed to assist education program directors and school nurses with understanding the state's lead screening requirement for enrollment into school or licensed child care settings.

### **4. Proposal to Clarify the Lead Screening Requirements**

In January 1999, the RICLPPP re-designed the *Lead Screening and Referral Guidelines* that had been maintained since the early 90s. The purpose of the guidelines was to integrate the latest (1997) CDC recommendations for lead screening, and courses of action with Rhode Island's lead screening law. The guidelines have since been revised and updated in September 2000,

February 2002 and July 2004, to accommodate enhancement of services. The expansion of case management services through the development of statewide Lead Centers, and the ability to offer these services to greater numbers of children by decreasing the lead level eligibility status from 20 µg/dl to 15 µg/dl are two major enhancements in our efforts to further prevent and control lead poisoning in Rhode Island's children.

As published in the July 2004 edition of the "Lead Update" (<http://www.health.ri.gov/lead/family/update/July2004.pdf>, excerpt included below), the last modification of the *Lead Screening and Referral Guidelines* took place in July 2004, after several pediatricians were consulted and confirmed that they are routinely ordering a venous (or confirmatory test) for any child under six who had been screened with a capillary test between 10 and 19 mcg/dL. Prior to this change, RICLPPP monitored the capillary tests greater than or equal to 20 mcg/dL and sent a letter to providers recommending that a confirmatory test be done.

**Attention Providers: DOH Alters Blood Lead Screening Guidelines!  
Providers to Confirm CAPILLARY tests  $\geq$  10 mcg/dL as of July 1, 2004**

On July 1, 2004, the Rhode Island Department of Health will be releasing a revised version of the Pediatric Blood Lead Screening and Referral Guidelines. Currently, the Department of Health conducts follow-up (via a letter, telephone call, or both) to providers to ensure that a confirmatory venous test is done for children under the age of six who have a capillary test result greater than or equal to 20 mcg/dL. Starting July 1<sup>st</sup>, 2004, the blood lead level requiring a follow-up venous test will be reduced from 20 mcg/dL to 10 mcg/dL.

The guidelines for referrals to case management are also being revised. Currently, children under the age of six with a first time blood lead level, capillary or venous, between 15 and 19 mcg/dL are referred to case management. As of July 1, 2004, children with a first time blood lead level between 15 and 19 mcg/dL will be referred to case management only if the test result is based on a *venous* sample.

The revisions to the screening guidelines arose from an awareness of providers and case managers that many families in Rhode Island already desire and request venous confirmation before accepting services from the Lead Centers. Additionally, pediatricians throughout the state are already confirming elevated capillary tests with venous tests. In 2003, 68% (380 out of 556) of capillary tests between 10 and 19 mcg/dL were followed up with a venous test. As of July 1<sup>st</sup>, when the new guidelines are in effect, the Department of Health will continue to actively encourage pediatricians to confirm capillary tests greater than or equal to 20 mcg/dL, and will begin to provide support to confirm capillary tests between 10 and 19 mcg/dL. We expect that the changes in the guidelines and the additional support from the Department of Health will result in an even higher rate of confirmatory venous testing.

In early 2005, the RICLPPP completed a historical cohort study to determine the initial percent of Rhode Island children under the age of six that had been screened for lead and had a blood lead level greater than or equal to 15 mcg/dL for the first time, after 36 months of age. It was found that a very small percent<sup>2</sup> of children in this study had an elevated blood lead level for the first time at that age.

In Addition, in October 2005, the American Academy of Pediatrics (AAP) recommendations <http://pediatrics.aappublications.org/cgi/reprint/116/4/1036> for lead screening were published:

1. *Provide anticipatory guidance to parents of all infants and toddlers about preventing lead poisoning in their children. In particular, parents of children 6*

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<sup>2</sup> Of the 43,373 children included in the analysis, 63 children were either considered "persistent" or had at least one venous blood lead test result greater than or equal to 20 mcg/dL after the 3<sup>rd</sup> birthday for the first time.

*months to 3 years of age should be made aware of normal mouthing behavior and should ascertain whether their homes, work, or hobbies present a lead hazard to their toddler. Inform parents that lead can be invisibly present in dust and can be ingested by children when they put hands and toys in their mouths.*

- 2. Inquire about lead hazards in housing and child care settings, as is done for fire and safety hazards or allergens. If suspicion arises about the existence of a lead hazard, the child's home should be inspected. Generally, health departments are capable of inspecting housing for lead hazards. Expert training is needed for safe repair of lead hazards, and pediatricians should discourage families from undertaking repairs on their own. Children should be kept away from remediation activities, and the house should be tested for lead content before the child returns.*
- 3. Know state Medicaid regulations and measure blood lead concentration in Medicaid-eligible children. If Medicaid-eligible children are a significant part of a pediatrician's practice or if a pediatrician has an interest in lead poisoning, he or she should consider participating in any deliberations at the state and local levels concerning an exemption from the universal screening requirement.*
- 4. Find out if there is relevant guidance from the city or state health department about screening children not eligible for Medicaid. If there is none, consider screening all children. **Children should be tested at least once when they are 2 years of age or, ideally, twice, at 1 and 2 years of age, unless lead exposure can be confidently excluded. Pediatricians should recognize that measuring blood lead concentration only at 2 years of age, when blood lead concentration usually peaks, may be too late to prevent peak exposure.** Earlier screening, usually at 1 year of age, should be considered where exposure is likely. A low blood concentration in a 1-year-old, however, does not preclude elevation later, so the test should be repeated at 2 years of age. Managed health care organizations and third-party payers should fully cover the costs of screening and follow-up. Local practitioners should work with state, county, or local health authorities to develop sensitive, customized questions appropriate to the housing and hazards encountered locally.*
- 5. Be aware of any special risk groups that are prevalent locally, such as immigrants, foreign-born adoptees, refugees, or children whose parents work with lead or lead dust in their occupation or hobby and, of course, those who live in, visit, or work on old houses.*
- 6. In areas with old housing and lead hazards, encourage application for HUD or other moneys available for remediation.*
- 7. Keep current with the work of the national Advisory Committee on Childhood Lead Poisoning Prevention and any relevant local committees. Although there*

*is now evidence that even lower blood lead concentrations may pose adverse effects to children, there is little experience in the management of excess lead exposure in these children. Although most of the recommendations concerning case management of children with blood lead concentrations of 15 µg/dL should be appropriate for children with lower concentrations, tactics that decrease blood lead concentrations might be expected to be less and less effective as they are applied to children with lower and lower blood lead concentrations.*

Based on Rhode Island specific data, and in order to be consistent with the AAP recommendations, RICLPPP is proposing to modify the screening schedule to continue to require annual lead screening for children between 9 and 36 months of age, and allow discontinuance of screening if all tests done by 36 months of age were under 15 mcg/dL (thus, omitting the requirement to do another lead test AFTER 37 months of age prior to discontinuing). Under this proposal, the Rhode Island Rules and Regulations (located in its current form at <http://www.health.ri.gov/lead/family/about.php>), Section 3.1 "General Requirements" about lead screening schedule and provisions for discontinuance would be modified to read as follows:

**(b) Screening Schedule.** *All children in Rhode Island shall be screened for blood lead in accordance with the following schedule: Each child between nine (9) and thirty-six (36) months of age shall be screened for blood lead at least annually. More frequent blood lead screening of asymptomatic children less than thirty-six (36) months of age may be justified based on the child's residence, the condition of the housing where the child resides, and the prevalence of lead poisoning in the child's neighborhood. Each child between thirty-seven (37) and seventy-two (72) months of age shall be screened for blood lead annually, except as provided for in Subsection 3.1 (c) below. Children who are developmentally delayed shall receive blood lead screening tests at intervals appropriate for their developmental age. Children exhibiting signs or symptoms consistent with lead poisoning shall have an appropriate diagnostic evaluation, including a venous sample for blood lead determination, and shall not be considered appropriate candidates for a blood lead screening test.*

**(a) Discontinuance of Annual Blood Lead Screening.** *Annual blood lead screening for each child between thirty-seven (37) and seventy-two (72) months of age may be discontinued under the following circumstances:*

- (1) All of the child's blood lead screening tests conducted during the first thirty-six (36) months of life were less than fifteen micrograms of lead per deciliter (15 µg/dl) of whole blood; and*
- (2) The child's first blood lead screening test conducted between thirty-seven (37) and seventy-two (72) months of age was less*

**than fifteen (15) µg/dl; and THIS LANGUAGE WOULD BE REMOVED UNDER THE NEW PROPOSAL.**

*(3) The child has not moved to another residence; and*

*(4) The child's parent or guardian has not reported conditions at the residence which may pose a lead hazard. Such conditions include, but are not limited to, uncontrolled power sanding of a neighbor's house, renovation of the child's home involving generation of dust, or proximity to a known or suspected source of lead contamination; or*

*(5) The child reaches seventy-two (72) months of age.*

Input from the Advisory Committee is requested by the RICLPPP to discuss this matter prior to the implementation of this change. Then, the RICLPPP will make the proposed clarification in the *Lead Screening and Referral Guidelines* and will make it available to all pediatric providers, health care professionals and other interested parties, through direct mail, publications on the "Lead Update" and inclusion on the web site.

## **5. Current Lead Screening Activities and Quality Assurance Efforts**

Although screening rates in the state have been increasing steadily during the last few years, the RICLPPP has continued to invest remarkable efforts and tremendous creativity to enhance screening by establishing numerous strategic partnerships, utilizing the richness and completeness of the lead screening data in LESS, offering technical assistance and using every possible way to identify unscreened children and measure progress in screening. In Rhode Island, over 75% of the 18-month-old children are screened for lead at least once. However, the remaining 25% must still be reached and our efforts to further improve lead screening shall not cease. Fortunately, we count on several important partners and strategies to engage in the improvement of lead screening compliance, as summarized in Rhode Island's Lead Screening Strategies (appendix 2).

In the numerous efforts to enhance screening in the state, the RICLPPP relies on key partnerships with the MCOs and KIDSNET. KIDSNET data includes information on all children born in Rhode Island since January 1, 1997 and connects public health pediatric programs' data to pediatric providers and other users. Additionally, other partners engaged in the improvement of lead screening rates are the Immunization Program, the Head Start agencies, the FOP, the WIC Program, and the state Refugee Program. We recognize the critical role of these partnerships and express thanks to all of them for their commitment to the prevention of childhood lead poisoning through lead screening.

In the paragraphs below we detail the concept of such partnerships and include an up-to-date summary of efforts.

### **a. The Role of Medicaid In Lead Screening**

Rhode Island has a solid infrastructure for lead screening and case management (see case management in section IV) and has been receiving Medicaid reimbursement for these services since the early nineties. The RI Lead Poisoning Prevention Act passed in 1991 mandates that

analysis of all blood lead screening specimens be conducted by the Department of Health's Laboratory and universal reporting of all blood lead tests, which facilitates the surveillance and data collection in one, statewide system that is maintained by RICLPPP and also tracks case management activities. The RI Lead Law also requires insurance coverage (including Medicaid) for blood lead testing, and therefore has been using Medicaid reimbursement. In the early nineties, RICLPPP also reached an agreement with Medicaid to obtain reimbursement for the environmental investigations that are conducted in the homes of the Medicaid eligible significantly lead poisoned children. The reimbursement level for the environmental inspections is set at \$775, \$675 of which is for the actual inspection and the remaining \$100 for administrative expenses. Since October 2000, Medicaid also became a major player in the reimbursement of non-medical case management through the certification of "lead centers" that provide comprehensive support to families of significantly lead poisoned children.

We are frequently asked how the program has achieved such high rates of screening among children insured by Medicaid in Rhode Island. Clearly, the success of increased lead screening rates can be partially attributable to the RIte Care Program, the statewide managed care health program for Medicaid-eligible children. In 1992, the Rhode Island Department of Human Services (DHS) and the Rhode Island DOH prepared a 1115 Medicaid Waiver proposal for expanding health care access through a managed care model to children from birth through 8 years of age in families with incomes less than 250% of the federal poverty level. As part of that process, a research plan had to be developed, since under Medicaid law, 1115 waivers are considered research and demonstration projects. Blood lead screening was adopted as a performance indicator under this 1115 waiver.

One of the principle strategies of public health is the use of surveillance to develop disease control strategies. The department's DFH had developed one of the strongest MCH surveillance systems in the United States that included population based surveillance of births, deaths and hospitalization as well as program data documenting utilization of newborn screening, lead screening, WIC enrollment, home visiting and Early Intervention (EI) enrollment. Given this, the DFH was asked to develop a set of research hypotheses and measures of accountability that would eventually be used to develop managed care contracts for purchasing coverage for the newly eligible population as well as children previously categorically eligible for medical assistance in Rhode Island. The developed hypotheses included measures such as rates of low birth weight, utilization of early prenatal care, immunization coverage rates and finally childhood lead screening rates. The lead screening measure was selected based upon the data accessible to DFH through established mandatory laboratory lead screening reporting.

In 1993, the Health Care Financing and Administration (HCFA) approved the initial waiver proposal. Ultimately, the Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) requirement for lead screening by 18 months of age, as required under Rhode Island state law, was incorporated into the contracts with the four RIte Care managed care plans as a reference in the Rhode Island EPSDT Periodicity Schedule (appendix 3).

The July 1998 RIte Care contract revision included language pertaining to performance goals. The performance goals, developed with RIte Care health plan review, were grouped into three areas: administrative, access and clinical. The Rhode Island Department of Human Services (DHS) assessed health plan performance on these goals through on-site review and encounter

data review. Performance goal assessment criteria were provided to the plans. By 2000, performance goal review had been completed for calendar years 1998 and 1999, with several modifications in methodology.

In 1999, the first year that the state MCOs were offered incentives to improve performance in delivery of preventive pediatric services, RICLPPP received a request from one MCO whose encounter data showed very low rates of lead screening. This MCO believed that their encounter data systematically underestimated the true lead screening rate for their enrolled members and asked that the RICLPPP's database be used to make an independent estimate of lead screening among their enrolled population. This request led to the MCO receiving its incentive award and raised the awareness of the limitations of encounter data to assess performance for such preventive pediatric services. (Subsequently, a mechanism was identified and we are now working with the Rhode Island's three MCOs in a data sharing arrangement to assure lead screening as described in Section 6b. below.

In the early 2000s, the Center for Child and Family Health (CCFH) from the Rhode Island's Department of Human Services (DHS) initiated a monitoring program designed to provide quarterly performance information updates to the Rite Care Plans for a number of preventive health measures, including the initial lead screening. The Lead Screening Performance Goal, part of the Rite Care plans' contract at that time was as detailed below:

*Members who reach 18 months during the reference period will have had an initial lead screen within the preceding nine months.*

*Standard: 85 percent*

*Reference period: Calendar year 1999*

*Rite Care specific*

*Performance Assessment*

*Assessment is based on analysis of the encounter data edited and loaded by EDS no later than March 31, 2000.*

*Denominator: All children who reach 18 months of age during the reference period and who have been enrolled with the Health Plan at least 31 days.*

*Numerator: Of the children identified in the denominator, all those with an initial blood lead screen during the preceding nine months.*

In a most recent review of the goals established by Rhode Island's DHS (early 2005), the lead screening benchmark that is used to measure the MCOs lead screening performance is as follows:

*Area: Medical Home/Preventive Care*

*Goal: Children received at least one age appropriate blood lead screen prior to their second birthday.*

*Rite Care standard: 85%*

*Source of Measure: To be determined with Health Plan input*

RICLPPP has continued to work with the MCOs and DHS to provide data to measure each MCOs lead screening performance. Through the data exchange performed by the RICLPPP with MCOs'

data, it was found that in 2004, 84% children were screened for lead at least once by their second birthday. No doubt, Rhode Island's Medicaid agency has provided the foundation and support to engage the MCOs partnerships with RICLPPP in a measurable, effective way.

### **b. Data Exchange with Managed Care Organizations**

A genuine collaboration between MCOs and public health is currently underway. The initiative developed from conversations between the Department of Health's Director and representatives from the MCOs in an effort to formulate quality assurance strategies for improving access to children's preventive services. Capturing the momentum to build commitment, on March 1, 2000, the Division of Family Health's leadership, including representatives from the Lead, Immunization, KIDSNET, FOP and WIC Programs met with representatives from each of the MCOs, United Health Care of New England, Neighborhood Health Plan of Rhode Island and Blue Chip. Different options were discussed and finally, due to data availability, resources and other issues, lead screening was selected as the first quality assurance effort between the MCOs and the Department of Health.

The basis for this strategy rests on the fact that lead screening documentation is primarily in one or more of three places: the RICLPPP's database, the laboratory reports in providers' offices and the actual (coded) insurance claims submitted to the plans for payment purposes, but not all the results are in all three data depository locations. Hence, easy and complete access to evidence of lead screening could only be done utilizing a unique approach, joining resources and expertise.

Given the above, the actual content of the effort was defined at a later meeting in early April 2000. A data match was to be conducted as a pilot project. A one-month birth cohort was selected and criteria defined (children who were 22 months old, are actively enrolled in one of the MCOs, had no lead screening claim submitted to the plans and resided in Rhode Island) to prepare a file. Each of the MCOs submitted their file, which then was matched against information on the RICLPPP's database, to determine whether or not the children had evidence of lead screening. Results of the data match were provided to each of the MCOs, who in turn conducted another level of review, asking providers to supply us with evidence of lead screening, if existent in the individual's chart, or contact the patient to order the test.

A variety of efforts were made on the part of the Health Plans, the individual providers and the RICLPPP to obtain the greatest benefit from this effort. As a result of the data match conducted on a pilot basis in 2000, it was found that:

- The lead screening rate for the one-month birth cohort was 86%, leaving a 14% of unscreened children by the time they were 22 months of age.
- Some technical glitches in the data transfer (from Stellar to KIDSNET, from Cerner –the State Laboratory computer system- to Stellar) were identified. A corrective plan was immediately put in place.
- An important proportion of the unscreened population have had no contact with the provider, or had an unknown address or their place of residence was questionable (it was not clear whether or not they were still in the state). An individually tailored outreach approach would be needed for this population.

During August and September 2000 there were dialogues to establish the specific outreach contact each of the Health Plans would offer to the individual children identified as not having lead screening by the data match. It was then decided that due to the unavailability of telephone numbers and to assess family status and barriers to care, a one-on-one contact preferably in the home would be desirable. On a pilot basis, the Family Outreach Program offered to conduct a home visit to each of the families fitting the group for which the provider had already made an effort and was unsuccessful. Investments made in terms of time and staff, findings/outcomes of the visits, and potential benefits of effort continuation will be evaluated in the next phase.

Meanwhile, the group formed by the Department of Health representatives and the MCOs agreed to establish an ongoing collaboration around the data exchange effort. Based on the findings of the pilot project, the ongoing effort will be conducted on a quarterly basis and will be reassessed as needed. The content of the ongoing partnership approach with the MCOs is described below:

The population is defined as follows:

- 22 month old children
- Actively enrolled in the MCOs Plan
- No CPT 83655 code on individual Plan's claims data
- Resident of Rhode Island

The content of the approach:

- Selection of (3 month) birth cohort
- The MCOs will submit the data file following specified criteria
- The RICLPPP will conduct the data match and prepare a file with results for each of the MCOs
- MCOs will send a standard letter to providers with list of unscreened children.
- Providers will either:
  - Provide evidence that a lead screening test has been done,
  - Make an effort to screen those children, or,
  - Notify the Plans if their efforts were unsuccessful and further assistance is needed.
- For those cases where providers expressed further assistance need, there will be an outreach effort made, either by the Family Outreach Program to provide a one-on-one home visit or some form of individual outreach contact proposed by the Health Plans and agreed upon by the group.
- Results will be evaluated and next effort initiated.

The effort described above was continuously conducted, and other assessments made and the strategy has been modified a number of times given the findings of the data match. By the summer of 2004, the data match had been conducted for 13 birth cohorts, and screening rates varied as shown in the table below.

| Match                  | RI Births     | Enrolled in the Plan | SCREENING RATE              |                       | BEFORE                   |                        | AFTER                           |                       | Net gain    |
|------------------------|---------------|----------------------|-----------------------------|-----------------------|--------------------------|------------------------|---------------------------------|-----------------------|-------------|
|                        |               |                      | By MCO Claims               |                       | 23-25 months of age      |                        | 30-32 months of age             |                       |             |
|                        |               |                      | Screened by MCO Claims data | Plans' Screening Rate | Screened after the match | Initial Screening rate | Screened after the intervention | Ending Screening rate |             |
| *Q1 <sup>3</sup>       | 3,955         | 2,510                | 845                         | 33.7%                 | 1,886                    | 75.1%                  | 2,111                           | 84.1%                 | 9.0%        |
| Q2                     | 2,994         | 2,351                | 1,140                       | 48.5%                 | 1,978                    | 84.1%                  | 2,105                           | 89.5%                 | 5.4%        |
| Q3                     | 3,129         | 1,778                | 859                         | 48.3%                 | 1,430                    | 80.4%                  | 1,554                           | 87.4%                 | 7.0%        |
| Q4                     | 2,812         | 1,611                | 776                         | 48.2%                 | 1,281                    | 79.5%                  | 1,405                           | 87.2%                 | 7.7%        |
| Q5                     | 2,833         | 1,608                | 775                         | 48.2%                 | 1,385                    | 86.1%                  | 1,437                           | 89.4%                 | 3.2%        |
| Q6                     | 3,044         | 1,619                | 894                         | 55.2%                 | 1,368                    | 84.5%                  | 1,474                           | 91.0%                 | 6.5%        |
| Q7                     | 3,442         | 1,743                | 952                         | 54.6%                 | 1,482                    | 85.0%                  | 1,532                           | 87.9%                 | 2.9%        |
| Q8                     | 3,233         | 1,559                | 911                         | 58.4%                 | 1,346                    | 86.3%                  | 1,406                           | 90.2%                 | 3.8%        |
| Q9                     | 3,157         | 1,501                | 834                         | 55.6%                 | 1,247                    | 83.1%                  | 1,343                           | 89.5%                 | 6.4%        |
| Q10                    | 3,445         | 1,603                | 883                         | 55.1%                 | 1,292                    | 80.6%                  | 1,423                           | 88.8%                 | 8.2%        |
| Q11                    | 3,566         | 1,744                | 956                         | 54.8%                 | 1,393                    | 79.9%                  | 1,568                           | 89.9%                 | 10.0%       |
| Q12                    | 3,134         | 1,545                | 1028                        | 66.5%                 | 1,279                    | 82.8%                  | 1,340                           | 86.7%                 | 3.9%        |
| Q13                    | 3,285         | 1,472                | 1006                        | 68.3%                 | 1,178                    | 80.0%                  | 1,307                           | 88.8%                 | 8.8%        |
| <b>Total/<br/>Mean</b> | <b>42,029</b> | <b>22,644</b>        | <b>11,859</b>               | <b>52.4%</b>          | <b>18,545</b>            | <b>81.9%</b>           | <b>20,005</b>                   | <b>88.3%</b>          | <b>6.4%</b> |

Given the success of the partnership, but considering the resource-intensive quality of the effort on the part of RICLPPP, added to the loss of staff in RICLPPP, it was agreed in the summer of 2004 that the data exchange effort would be temporarily put on hold until such time when resources become available.

In early 2005, when the vacancy was filled, RICLPPP convened the group with the MCOs and the Rhode DHS and held discussions about the methodology for the effort. At that time, the DHS had changed the benchmark to measure lead screening performance of MCOs, to require appropriate lead screening by 24 months of age, and establishing a minimum of 85%. Given this new requirement in the performance for MCOs, the group agreed that the data match would only be performed twice a year, once in the fall, and once in the spring. The data match conducted in the spring will be submitted to DHS and will be used to document lead screening performance in each of the MCOs. The population to include in the data match was also modified. Under this new schedule, MCO's will provide a birth cohort of children who turn two years old in the calendar year. RICLPPP provides a list of unscreened children to the MCOs so the plans can contact the child's pediatrician to notify and encourage lead screening for their patient. Six months later, this same birth cohort is re-matched against RICLPPP data, to assess if the outreach attempts were successful.

<sup>3</sup> This quarter included a 4-month cohort. All others were for 3 months.

The RICLPPP conducted the data match in the spring of 2005 and found that the MCOs are screening 84% of their enrollees by 24 months of age.

Additionally, the group discussed options that may simplify and/or streamline this resource intensive data match. One of the options was to engage MCOs in the effort to encourage pediatric providers to participate in KIDSNET, which will allow them to run reports of “never screened” children in their practice from their own offices, on demand.

MCOs agreed to work with RICLPPP and KIDSNET on this task, and included notices on their respective newsletters to that effect. RICLPPP and KIDSNET continue to be part of the group and will continue to work on the effort to engage all providers in KIDSNET, and eventually make sure they use KIDSNET as a tool to measure their own lead screening performance on an ongoing basis, rather than once a year.

Additionally, the group discussed the need of having a written agreement that reflects the efforts that MCOs and RICLPPP invest in the data match to identify unscreened children. This dialogue resulted in the design of a Memorandum of Understanding (MOU) signed by RICLPPP and each of the three MCOs in November of 2005, that delineates the content of the partnership (appendix 4).

This data exchange with the MCOs is one of the key successes of the RICLPPP and is a model that is constantly mentioned at several local and national forums as a model of collaboration that should be replicated.

### **c. The Role of KIDSNET in Lead Screening**

Since 1993 RICLPPP has maintained an electronic database that captures all lead screening results. In 2003, all data housed in the Stellar database was transferred to a new surveillance system, “LESS”, which has enhanced capability for case management tracking, linkage between the child’s blood lead tests and the environmental interventions, and included powerful tools for report generation. In spite of this surveillance system upgrade, RICLPPP’s LESS database only kept data for children TESTED, and was unable to identify those who are NOT TESTED. KIDSNET started collecting demographic information on all Rhode Island’s births occurring since January 1, 1997, and RICLPPP started exporting lead screening data to match those births in KIDSNET. This way, RICLPPP had for the first time the opportunity to use population-based data to establish a denominator of a statewide lead screening rate, as well as to identify unscreened children.

In the spring of 1998, the first KIDSNET children were turning 15 months old and therefore at an age when lead screening must be performed and could be measured using the entire population. Since this time, KIDSNET’s capabilities and maturity have increased and have provided a mechanism to measure and enhance lead screening in Rhode Island children. Utilizing data from KIDSNET, RICLPPP has put in place numerous efforts directed to reach parents, providers and other partners in efforts to increase screening rates. Those efforts are summarized below.

**RICLPPP SCREENING STRATEGIES USING KIDSNET**

| <u>APPROACH TYPE</u>   | <u>POPULATION</u>   | <u>FREQUENCY</u>  | <u>METHOD</u>   | <u>FEEDBACK/<br/>NEXT STEPS</u>   |
|--|---|---|---|---|
| <b>1. Parent Approach</b> Post cards sent to all children turning 12 months of age<br><u>Source: KIDSNET</u>       | All children born in Rhode Island turning one year of age                       | Report, Labels and mailing conducted weekly                                 | Reminder Post Cards mailed to Parents to have their children screened at their upcoming 12 Month Well-Child Visit                                 | Re-send cards to any new addresses. Update KIDSNET with new addresses   |
| <b>2. Parent Approach</b> Letter sent to parents of unscreened 18-month old children<br><u>Source: KIDSNET</u>     | All children active in KIDSNET turning 18 months of age                         | Report, Labels and mailings conducted monthly                               | Letter sent to Parents (with other educational materials) encouraging them to have their children screened at upcoming 18 Month Well-Child Visit. | Re-send letters to any new address. Update KIDSNET with new addresses   |
| <b>3. Provider Approach</b> Providers use of KIDSNET's report of patients never screened<br><u>Source: KIDSNET</u> | All KIDSNET participating pediatric providers seeing patients born since 1/1/97 | Providers can run the report on demand. Monitoring is done by CLPPP monthly | RICLPPP reviews the KIDSNET web usage report monthly  | Usage of the reports is published in the KIDSNET newsletter monthly. Frequent (providers) users are recognized at annual Lead Month Event users |
| <b>4. WIC approach</b> Report generated from KIDSNET<br><u>Source: KIDSNET</u>                                     | Active children under the age of 5 with no lead test                            | Conducted as often as WIC agencies can conduct QA                           | A report is generated from KIDSNET and sent to the WIC Program's Coordinators for review and follow up  | N/A   |

**1. Parent Approach: Post cards sent to all children turning 12 months of age**

For the last several years, KIDSNET has generated lists of all children turning 12 months old and mails a postcard to parents as a reminder that at that age it is the first time that children should be tested for lead, and therefore should ask their child's pediatrician about the lead test. It is expected that this effort will continue in the future.

**2. Parent Approach: Letter sent to parents of unscreened 15-month old children**

Since July 1998, KIDSNET started generating lists of children turning 15 months with no evidence of a lead screening test in the system. It is important to mention that although lead screening is recommended to start at any time after 9 months of age, it was decided to allow some time and start generating reports for children 15 months old. This extra time ensures further data collection as well as allows for missed and rescheduled appointments.

For over seven years, RICLPPP has sent a monthly letter (appendix 5) to parents of 18-month-old children with no evidence of a lead test, encouraging them to have their children tested and/or ask their child's pediatrician about the lead test.

Initially, the goals of this initiative were:

1. To identify children with no evidence of lead screening,
2. To identify barriers to timely screening
3. To update KIDSNET addresses

For purposes of identifying possible barriers to screening, a parent-to-parent telephone survey conducted months after the outreach letter was sent was also made part of the initiative. The pilot survey was completed during the fall of 1998 and provided the basis to establish a systematic, on-going survey that helped us to identify lead screening deterrents.

The most common response from parents was the assumption that lead screening is automatically performed at the child's annual check up visit. Other barriers identified by the survey include parents' lack of awareness that they need to have their children tested, time investment needed to mobilize the family to an off-site laboratory, and parents' concerns regarding the infrequent but traumatic experience to collect a blood specimen in a young child.

The RICLPPP's Parent Consultant systematically contacted parents of children screened and unscreened according to the KIDSNET system for about six months. Specific questions asked include the reasons for having their child tested or not tested, insurance and primary care provider availability, as well as proximity of laboratory location for conducting the test. Findings of the telephone interviews conducted during the first year of the effort have been shared with the Advisory Committee.

The telephone interviews have served as a qualitative assessment tool that has already informed the program about screening barriers that need to be considered for policy development. Continuation of the interviews on a systematic basis and/or modification will be reassessed. Monthly correspondence to parents, however, is an established and ongoing effort.

### **3. Provider Approach: Providers use of KIDSNET's report of never screened children in their practice**

KIDSNET centrally generated in-house reports of "never screened" children who are 15 month old or older, who were enrolled in a specific practice and have no evidence of lead screening in KIDSNET. This report generation capacity was used for the first time in May 2000, as an additional outreach component of "Lead Poisoning Prevention Month." At that time, only providers participating in KIDSNET received the report. It was clearly indicated the report was an available tool to assist in lead screening, and it may not be completely accurate due to the fact that KIDSNET may not have been notified of patients transferred out of the practice, some laboratory results may not have been reported, or children born out of state may not have been listed.

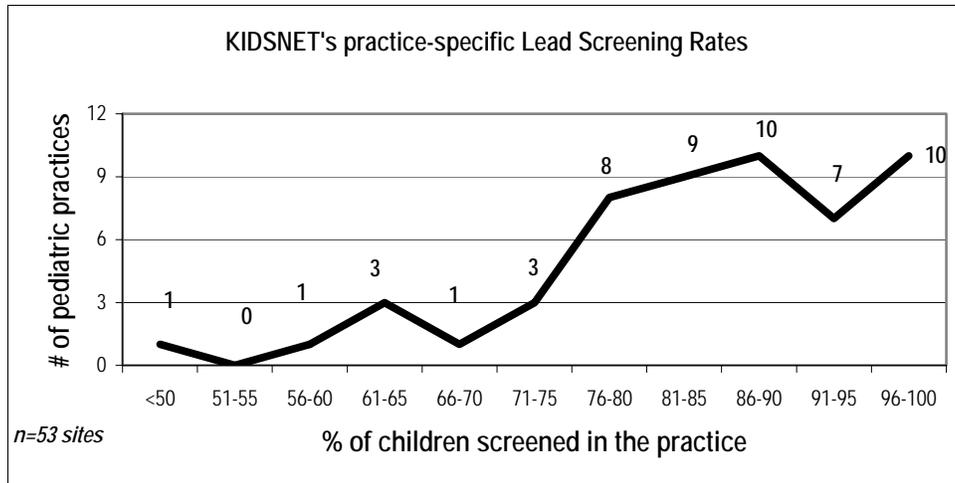
As a result of feedback received from the providers who used the "never screened" report, it was established that the three reasons above stated were present and that the report needed to have a higher degree of accuracy before it was massively and routinely disseminated to providers for

quality assurance purposes. It was then decided to incorporate an additional effort in the Lead Screening Quality Assurance strategy.

The newly formulated initiative consisted of selecting providers with a high number of patients 15 month old or older, or attending a provider's request, and providing individual Quality Assurance to the provider. The steps for this effort were:

- Select a provider
- Generate (in house) the KIDSNET "never screened" report
- Conduct manual/electronic review in the Lead program's database to ensure all data has been properly transferred to KIDSNET
- Identify the number of children with no evidence of lead screening in the Lead database
- Contact the provider and schedule a chart review on site, conducted by RICLPPP's staff
- Evaluate findings/formulate recommendations
- Communicate findings/recommendations to the individual provider with their individual, confirmed lead screening rate

This effort was successfully conducted in 53 pediatric practices in 4 years from October 2000 through August 2004. Lead screening rates identified in those practices are graphed below.



In early 2004, KIDSNET system became web enabled and was rolled out to all participating pediatric practices. With this upgrade, practices were also provided with the ability to generate the report of "never screened" children in their practice from their own office, on demand. With this system enhancement, RICLPPP decided to discontinue the chart review and manual report generation, and engaged in a different strategy to encourage providers to use the report now available at their own practice.

In 2004 RICLPPP started monitoring the frequency and practices that have generated the lead screening report in their practices, and KIDSNET includes a note on their monthly newsletter recognizing those practices that are using the report.

To date, 104 of the 120 participating practices in KIDSNET have Internet access and are able to run the report on demand. Those practices that lack Internet access have been offered the ability

to request the report to be mailed to them as often as needed, but no requests have been registered from those practices thus far.

For Lead Month in May 2005, RICLPPP presented Certificates of Appreciation to 10 KIDSNET participating pediatric providers who used the lead screening report at least eight times during 2004. The RICLPPP plans to continue to monitor the usage of the report, and is working on an evaluation study to assess any changes in screening rates in those practices that received the chart review in the past, compared to their current rate now that the KIDSNET web database allows them to monitor it on their own.

#### **4. The Women, Infants and Children (WIC) Program approach: Report generated from KIDSNET** See the section below for details on this effort.

##### **d. The Role of WIC in Lead Screening**

The WIC Program has been another strong partner since the early years when lead screening was not mandatory and years before managed care was implemented in the state. Serving the same population of young children, WIC is in a favorable situation to emphasize the importance of lead screening. WIC and RICLPPP strengthened their efforts related to lead screening by working with KIDSNET and allowing WIC agencies access to KIDSNET. With KIDSNET as a tool, WIC nutritionists review the lead screening status of participants scheduled for re/certification visits and document a nutritional risk if the WIC participant is a child with a blood lead level greater than or equal to 10 mcg/dL. The purpose of such a review is to assess lead screening compliance, provide appropriate nutrition recommendations, tailor the WIC food package and make referrals when appropriate.

During 2004 and 2005, the WIC Program has invested tremendous energy in the elaboration and implementation of a new information system. Given this high demand on WIC resources, the program put on hold the additional rollout of KIDSNET access to all WIC agencies and as of December 2005, only 5 WIC agencies have Internet access and are using KIDSNET for several purposes, including lead screening monitoring.

It is expected that the new WIC information system will be available in 2006, and will likely include lead screening information for those children participating in WIC, makes access to lead screening information easier and may eliminate the need to access KIDSNET for lead test data. When WIC new electronic system is available, the methodology for the lead screening partnership will be reassessed. However, WIC is committed and also required to coordinate health care services, and lead screening monitoring, referral and nutritional education will continue to be included in services provided to WIC participants.

##### **e. Lead Screening for Uninsured Children**

Access to free lead screening for uninsured children is provided through the continuing support of two hospital-based clinics located in Providence, Rhode Island. The clinics are funded to provide accessible lead screening services as well as immunization services to hard-to-reach populations and to link families to permanent sources of primary health care. The clinics offer services in a culturally sensitive and non-threatening environment and provide culturally and linguistically appropriate health education materials.

The clinics have been operating since January 1999. As of December 31, 2004, there have been 371 children screened for lead in the free clinics. A summary of information collected is provided below.

| # Of Lead Screenings Completed by Clinic | # Of Lead Screenings By Year | Insurance Status Of Children Screened |
|--|------------------------------|---------------------------------------|
| St Joseph's Hospital: 328                | 1999: 23                     | Uninsured: 309                        |
| Hasbro Children's Hospital: 42           | 2000: 11                     | Insured: - 13                         |
| Unknown: 1                               | 2001: 78                     | Unknown: 49                           |
|  | 2002: 72                     |                                       |
|  | 2003: 78                     |                                       |
|  | 2004: 109                    |                                       |
| Total= 371                               | 371                          | 371                                   |

#### f. Lead Screening for Refugee Children

On December 6, 2004, the CDC issued an urgent letter to managers of Childhood Lead Poisoning Prevention Programs across the United States. The letter notified program managers that a number of refugee children newly arrived from Africa had been identified with elevated blood lead levels. Medical records of these children had shown that the poisoning occurred after the children's arrival into the United States. In response to these cases, the CDC issued *Recommendations for Lead Poisoning Prevention in Newly Arrived Refugee Children* <http://www.cdc.gov/nceh/lead/Refugee%20recs.htm> to help guide states in preventing lead poisoning in this at-risk population, and to help states identify refugee children suffering from elevated blood lead levels. In response to the CDC guidance, the RICLPPP worked closely with the RI Department of Health's Refugee Health Program to develop lead screening guidelines specific to the refugee population, and to facilitate the identification of children with elevated blood lead levels and those children who are not screened in a timely fashion. Major highlights of the Rhode Island Department of Health's *Lead Screening and Referral Guidelines for Refugee Children* (appendix 6) include:

An initial venous blood lead screening for children ages 6 months to 16 years of age is required by the Rhode Island Refugee Health Program within 90 days of arrival (recommended within 30 days of arrival);

All children ages 6 months to 16 years should receive a follow-up venous lead test within 3 to six months of the initial blood lead screening;

Families of children with a venous level  $\geq 15$  mcg/dL are referred to a lead center for non-medical case management;

Families of children under the age of six with a venous level  $\geq 20$  mcg/dL, or a persistent venous level of 15-19 mcg/dL, are referred for an environmental inspection.

To ensure proper tracking of refugee children, the RICLPPP and the Rhode Island Refugee Health Program entered into a data sharing agreement in March of 2005. As refugees arrive in Rhode Island, they are entered into the Refugee Health Program's database. A list of refugee arrivals under the age of 16 are provided to the RICLPPP, which then ensures that the initial blood lead screening took place within 30 days of arrival. If the initial screening did take place, the

RICLPPP follows-up to ensure that a second screening occurs within 3 to 6 months of the initial test.

If the child was not initially screened, RICLPPP and Refugee Health work with the child's health care provider and the Refugee Resettlement Agency to ensure that the initial screening takes place. Through this data sharing initiative, the RICLPPP and the RI Refugee Health Program have established a solid system through which to identify unscreened refugee children and to ensure proper follow-up for refugee families.

Additionally, the RICLPPP has worked on outreach strategies to educate the critical partners about the importance of lead screening in refugee children and to alert providers of the new recommended guidelines. The Outreach and Education Coordinator for RICLPPP met with the Rhode Island Refugee Health Committee January 2005 to alert the agencies of upcoming changes to the guidelines, and to give an overview of lead poisoning, lead poisoning prevention, and the resources available to refugee families. The RICLPPP has also utilized its bi-monthly publication, the Lead Update, to disseminate information to health care providers and community agencies that work with refugee families. The RICLPPP will continue to work with the RI Refugee Health Program and the Rhode Island Refugee Health Coordinator to disseminate information as necessary to its partners.

#### **g. The Annual School Immunization Survey**

Another important ongoing partnership in quality assurance efforts involves the Annual School Immunization Survey conducted by the Immunization Program. The collaboration between the RICLPPP and the Immunization Program is based on the need to address childhood health issues in comprehensive ways with the consideration that children at risk for lead poisoning share many of the same socioeconomic barriers as children who are under-immunized. The survey is distributed to all daycare centers, Head Start programs and schools to assess immunization status of enrolled children. Since documentation of lead screening is also a requirement for enrollment, a question to assess the number of children under 6 (12-71 months) years of age without evidence of lead screening was added to the survey in 1999. The table below illustrates the percentage of children with documentation of lead screening in their school health record.

**Percentage of children with documentation of lead screening in their school health record - 1999-2004:**

| <b>School Program</b> | <b>1999</b> | <b>2000</b> | <b>2001</b> | <b>2002</b> | <b>2003</b> | <b>2004</b> |
|-----------------------|-------------|-------------|-------------|-------------|-------------|-------------|
| Daycare               | 72%         | 82%         | 84%         | 83%         | 84%         | 85%         |
| Head Start            | N/A         | N/A         | 75%         | 78%         | 83%         | 85%         |
| Kindergarten          | 55%         | 72%         | 80%         | 80%         | 83%         | 84%         |

In addition to the school survey, documentation of lead screening was assessed from a sample of children aged 12-24 months in private provider offices and community health centers. In 2002, the program assessed 814 records of children who were seen at private providers' offices, and 535 records of children who were seen at community health centers. The results indicate that children who were seen at private provider offices had lower rates of lead screening compared with children who were seen at community health centers. Of the 814 children seen at private

provider offices, 639 (78.5%) had documentation of lead screening, compared with 501 (93.6%) of the 535 children seen at community health centers.

Percentage of children 12-24 months of age with documentation of lead screening in their medical home record - 2001-2002:

| Medical Home Site          | 2001  | 2002  |
|----------------------------|-------|-------|
| Private Provider Practices | 69.5% | 78.5% |
| Community Health Centers   | N/A   | 93.6% |

#### **h. Lead Screening Reports**

The Rhode Island Childhood Lead Poisoning Prevention Program conducts numerous analyses on the lead screening data that are collected through the statewide surveillance program. These analyses are reported annually in several publications and on the web.

*Childhood Lead Poisoning in Rhode Island, The Numbers* is a publication that provides an overview of the lead poisoning problem at the state level. This report contains lead poisoning information over time, including screening information, incidence, prevalence, case management statistics, and environmental inspection data. In addition to being posted on the web, this report is distributed throughout the state to physicians, policy makers, researchers, and advocacy groups.

City-specific reports outlining the lead poisoning problem at the community level are created for Central Falls, Newport, Pawtucket, Providence, West Warwick, and Woonsocket- Rhode Island's six core cities (defined as a city where the child poverty level is greater than 15%, according to the 2000 Census). These reports contain lead poisoning information over time, including screening information, incidence, prevalence, and environmental inspection data. Each of these reports is posted on the web, as well as sent to the Mayor of the corresponding city.

Additional city-specific data for all of Rhode Island's cities and towns are posted on the web. These data include screening rates for all children for the most recent year, screening rates for children entering kindergarten, and incidence and prevalence data for the past ten years.

The information contained in the annual publications and posted on the website may be informative for parents, health care practitioners, and the general public. These data may also assist policy makers and city officials in better understanding the lead poisoning problem in Rhode Island.

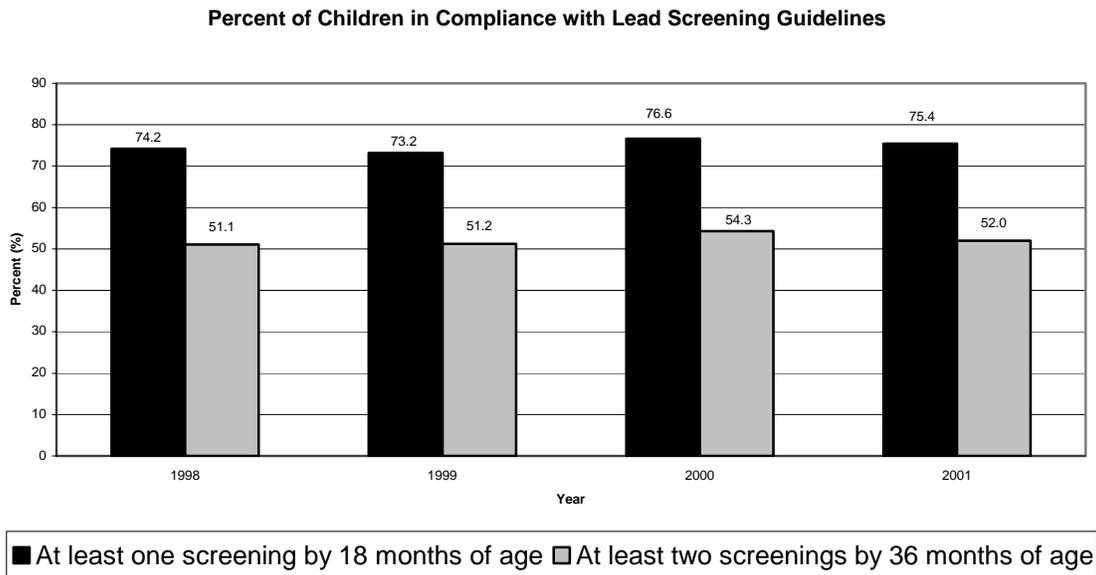
#### **6. Evaluation and Outcome Measures of Lead Screening**

To evaluate lead screening in Rhode Island, we look at the percent of children in compliance with the screening guidelines. The outcome measures that we use are the percent of children with at least one lead test by 18 months of age and at least two lead tests (at least 12 months apart) by 36 months of age. In order to calculate percentages, we use childhood population data from

KIDSNET, Rhode Island's integrated child health information system. The distribution of Rhode Island children screened once by 18 months of age is mapped in appendix 7.

Approximately 75% of Rhode Island children born between 1998 through 2001\* were screened for lead poisoning at least once by 18 months of age, and 52% of these children were screened at least twice by 36 months of age, with each test at least 12 months apart from the other. This indicates that although the majority of children are being screened for lead by 18 months of age, efforts must continue to focus on screening children as they approach 36 months of age.

See the graph below illustrating overall lead screening performance utilizing these two benchmarks.



## 7. An Outlook to the Future

As RICLPPP continues to work to achieve the ultimate goal to eliminate lead poisoning by 2010<sup>4</sup>, lead screening (and other secondary prevention) efforts continue to be an important program's priority and must continue to be measured using the two benchmarks of one test by 18 months of age, and 2 tests by 36 months of age, 12 months apart.

RICLPPP is also observing the latest recommendations from the AAP and is therefore proposing to modify the lead screening guidelines to be consistent with the Academy's latest publication. Our efforts in lead screening will continue. In the upcoming years, RICLPPP will continue to work in partnership with other programs and continue to identify strategic efforts that will not only

\* Birth cohorts beyond 2001 have not been calculated because those children had not yet turned 36 months of age by the time this report was prepared.

<sup>4</sup> "To decrease the number of new cases of lead poisoning (defined as a blood lead level of 10 mcg/dL or more) in children under six years of age in all Rhode Island communities, without displacing children, decreasing lead screening rates, or decreasing affordable housing"

screen children at the appropriate ages, but also to engage in efforts to reach the unscreened population. Efforts and partnerships include:

- Utilizing KIDSNET as a tool to measure, enhance and promote screening among health care providers,
- Conducting data matches with data from the MCOs,
- Utilizing KIDSNET to identify never screened WIC active participants,
- Working with the Refugee Health Program to screen the refugee population,
- Monitoring use of the lead screening information in KIDSNET by Head Start agencies,
- Partnering with Early Intervention to coordinate and enhance lead screening,
- Working with the Immunizations Program's Annual School Survey,
- Conducting other analysis and informing partners and advocates about lead screening efforts and underscreened population,
- Working with the FOP to enhance lead screening in the population they serve.

## **SECTION III. CAPACITY TO ANALYZE BLOOD LEAD SCREENING AND ENVIRONMENTAL LEAD DUST CLEARANCE SAMPLES AND ELECTRONIC REPORTING**

### **1. Background**

Since the formulation of Rules and Regulations to implement the Lead Poisoning Prevention Act of 1991, all blood lead screening specimens collected by and/or ordered by health care providers or professionals must be submitted to the Rhode Island Department of Health Laboratory for analysis. Specifically, the Regulations state the following:

#### ***3.2 Childhood Blood Lead Screening.***

*Health care providers shall ensure that childhood blood lead screening is conducted either by venipuncture or by capillary blood lead sampling in accordance with the following requirements:*

*(a) Screening samples. All blood lead screening test samples, including venipuncture screening samples and capillary blood lead samples, taken from children under six years of age at the request of a physician or other health care provider licensed in Rhode Island, or as part of a child health program partially or fully funded by State funds or administered by any State agency, shall be submitted to the State laboratory for analysis, unless the Department has approved use of another laboratory.*

*(b) Samples submitted to the State Laboratory. All blood samples submitted to the Department laboratory for analysis shall be accompanied by a completed laboratory requisition form, including all data necessary for reimbursement by insurers, and shall be packaged in accordance with procedures established by the Department laboratory.*

### **2. Laboratory Capacity for Blood Lead Specimens and Environmental Sample Analysis**

The Department of Health Laboratory supports RICLPPP by operating two separate lead testing laboratories, the Blood Lead Laboratory and the Environmental Lead Laboratory. The State Laboratory has a courier service which picks up blood lead specimens as well as other clinical specimens from over 20 health care centers and hospitals. Results of analysis of blood lead specimens are sent to the submitter's address as listed on the laboratory requisition form. An additional task performed by the State laboratory involves billing insurers. Submitters of specimens can assist the State in this task by appropriately recording the patient's insurance information on the requisition form. The results of analysis of blood lead specimens are sent to the ordering provider or specimen submitter, or both, if it's so indicated on the requisition form. The State Laboratory provides requisition forms and supplies for lead screening.

The Blood Lead Laboratory tests approximately 25,000 capillary or venous blood specimens each year. Blood lead levels are determined using graphite furnace atomic absorption (GFAA)

spectrophotometry. The method involves diluting the specimen with a matrix modifier solution that contains nitric acid, Triton X-100 and ammonium phosphate. Quality control samples are diluted in the same manner before analysis. The Laboratory has two GFAA instruments and each instrument is equipped with Zeeman background correction. The instruments are interfaced with a clinical Laboratory Information Management System. The Blood Lead laboratory is CLIA-certified and participates in the monthly proficiency scheme administered by the Wisconsin State Laboratory of Hygiene.

The Environmental Lead laboratory tests environmental samples (dust wipes, paint chips and soil) for lead content. Samples submitted to the laboratory by HEALTH inspectors are first acid digested using microwaves. Lead content of the digested samples is determined using Flame Atomic Absorption spectrophotometry. Annual volume of approximately 3,000 samples consists primarily of clearance dust wipes. This laboratory also provides analytical support for special programs, such as The *Keep Your Baby Lead Safe* (KYBLS) Program and the "10-14" (pilot environmental assessment program for homes of children with blood lead levels of 10-14 ug/dL). The Environmental Lead laboratory is accredited by the American Industrial Hygiene Association (AIHA) for all matrices of interest, and participates in a quarterly ELPAT proficiency-testing program.

Blood lead is determined on fingerstick and venous specimens by graphite furnace atomic absorption (GFAA) spectrophotometry. The method involves diluting the specimen (1:16) with a matrix modifier solution that contains nitric acid, Triton X-100 and ammonium phosphate. Quality control samples are diluted in the same manner before analysis. The Laboratory has three GFAA instruments and each instrument is equipped with Zeeman background correction. The instruments are interfaced with a clinical Laboratory Information Management System. Additional questions can be directed to Ewa King, PhD, at 401-222-1999

RICLPPP has authorized two external laboratories to analyze blood lead specimens. Both of these laboratories are hospital based, located in inner city neighborhoods and have an on site lead clinic that provides medical case management to lead poisoned children. One of the many requirements to receive this authorization is the ability to report all blood lead tests electronically to RICLPPP. The Policy for Lead Screening Analysis (appendix 8) defines the criteria necessary for a laboratory to become authorized to analyze blood lead specimens in Rhode Island.

### **3. Analysis of Lead Clearance Samples**

As indicated above, the RICLPPP utilizes the State laboratory for all field samples collected during inspections, re-inspections, investigations of illegal activities and clearances conducted by the RICLPPP Environmental Lead Program staff. All staff members in this unit are licensed as certified Environmental Lead Inspectors/Environmental Lead Inspector Technicians and have had extensive class and field training in the proper collection of samples for analysis. All samples are handled utilizing chain of custody forms that were developed in coordination with the laboratory to meet laboratory criteria. Clearance samples are required post abatement and prior to issuance of lead safe certification. In the instances when sample results are above the required standard, samples are retaken once an additional clean up has been done. The laboratory has developed a priority scheme so that environmental samples are analyzed as "rush" in emergency situations

such as hospitalized children and illegal abatement activities where we can obtain results the same day or next morning dependent upon the time delivered.

All open environmental lead cases, including those that have been referred for prosecution, must receive lead safe certification from RICLPPP staff.

The Department of Health (DOH) conducts a quality assurance review of the comprehensive environmental lead inspection report that includes assessment and testing/sampling of all painted surfaces, water, dust and soil sampling utilizing a standard form developed for this purpose. All aspects of the report are assessed to ensure compliance with the requirements for inspections described in section 4.0 of the Rules and Regulations for Lead Poisoning Prevention. Once the inspection report has been approved, an official notification (1<sup>st</sup> Notice of Violation) is sent to the homeowner with the findings of the environmental inspection and contact person in DOH, along with information for proper lead hazard reduction, funding resources and a real estate disclosure packet. RICLPPP staff routinely conducts site consultations with property owners to assist them in understanding the contents of the report and develop timely strategies for correction of the lead hazards identified therein. Further follow up and enforcement of non-compliant homeowners is the joint responsibility of the DOH and the Attorney General's Office.

The number of services for lead poisoned children and the efficiency with which they are delivered have significantly increased and improved over the last few years in the state of Rhode Island. One significant improvement that occurred in 1998 involved the environmental inspections. Years ago, the timeframe for the completion of environmental inspections in the homes of lead poisoned children was several months. Since inspections were privatized in early 1998, that time has now decreased significantly, to somewhere between four to six weeks to one to two weeks from the time the blood lead result is available in the RICLPPP's database and until the inspection is offered. We will continue to ensure quality and timely inspection services for families with elevated blood lead levels.

#### **4. Electronic Reporting**

The Lead Elimination Surveillance System (LESS) was implemented in June 2003 and captures all lead screening data from 1993 to the present time. LESS is comprised of a relational database, a web-based user interface, and numerous support applications that capture blood tests and other lead related data.

RICLPPP receives an overwhelming proportion of records electronically, and conducts minimal manual data entry, only from sources for which electronic requirement may be too burdensome compared to the volume of data. The proportion of blood lead tests received for children 0-6 years of age has remained steady at approximately 32,000-34,000 for the last several years. In 2004, 94% of blood tests were received electronically, this number increased to 96.3% in 2005.

Each blood lead test is stored electronically in LESS. This relational database includes data on non-medical case management and environmental inspection activities. Each child with an elevated blood lead result requiring intervention is linked to a case management and environmental inspection case. The LESS database has improved the ability to track a child's blood lead history over time and has enhanced reporting capability. Several quality assurance reports have been developed and are shared with RICLPPP partners. For example, lead centers

receive a monthly report listing all cases open with their agency and information regarding the child's most recent blood lead level and the ordering physician.

At this time, all required data is reported electronically to CDC on an annual basis. Blood lead screening data is the source of incidence and prevalence measures reported on the RICLPPP web site, the annual data book and reports to leaders of Rhode Island's six core cities.

LESS is also the source utilized to conduct several of the data exchanges and record matching necessary to execute some of the partnerships RICLPPP has formed in the last few years, including the partnerships with the MCOs and the data from Section 8. Currently, the data matching is resource intensive and is conducted with a semi-automated process. As more partnerships are expected to be formed, and resources become even scarcer, RICLPPP needs to identify an improved methodology that allows for higher automation to match records.

LESS has improved significantly the efficiency with which RICLPPP can track and monitor cases referred to Lead Centers for case management. The system has great flexibility to generate a multitude of reports that are used in several areas for monitoring, surveillance, and program evaluation for quality improvement. It is expected that with greater flexibility, users' demands will also increase, and even though LESS represents a critical improvement in our surveillance capacity, system enhancements will still be needed in the future.

## **5. An Outlook to the Future.**

RICLPPP anticipates that the LESS database will continue to be utilized as the source for all child based and environmental intervention surveillance data collection through 2010 and beyond. As we progress towards the elimination of childhood lead poisoning, and RICLPPP must continue its partnership with the Housing Resources Commission (HRC) not only to meet the requirements of the Lead Hazard Mitigation Law but also for the identification of a housing database that can relate to LESS in some respect. It is expected that some enhancements will need to be made to allow the program to meet those requirements. Rhode Island also expects to maintain the Laboratory infrastructure to analyze blood lead and environmental samples in the future, and continue its obligation to report data to CDC.

Following are some of the major areas of effort that RICLPPP expects to make in the near future:

- Maintaining the LESS database as the surveillance source for RICLPPP,
- Working with CDC in a format that will allow LESS to submit data to the National Electronic Data Surveillance System (NEDSS) LEAD PAM,
- Implementing system modifications needed in order to report data as required by CDC,
- Maintaining laboratory capacity for the analysis of blood lead and environmental samples,
- Identifying enhancements to the LESS database to allow automated record matching with data from other sources, such as housing data for primary prevention activities.

## SECTION IV. CASE MANAGEMENT

*Case management of children with elevated blood lead levels involves coordinating, providing, and overseeing the services required to reduce their blood lead levels below the level of concern (10 mcg/dL)<sup>5</sup>.*

### 1. Background

In Rhode Island, the case management infrastructure, methodology and resources have changed dramatically in the last decade, due to changing resources and the changing epidemiology of elevated blood lead levels. In the early nineties, when the number of children with significantly lead poisoned levels (greater than or equal to 25 mcg/dL) was in the hundreds, RICLPPP prioritized the case management resources (inspections and home visits) to reach those with the highest lead levels, while those with the lower levels were not always reached. With only one or two case managers at the RICLPPP, case management was offered in the form of home visits to the families primarily to provide some lead education and to encourage families to bring their children to the Lead Clinic, managed by the St. Joseph's Hospital. At the Lead Clinic's visits, families were reinforced on the techniques to put barriers to exposure and were provided medical treatment. Due to the tight resources, home visits were only provided to those families missing Lead Clinic's appointments.

In the mid nineties, due to the loss of case managers and given that vacancies couldn't be filled due to the hiring freezes, the RICLPPP started referring significantly lead poisoning cases to the Family Outreach Program's home visitors and case management was limited to one to three visits to those families.

During that time, inspections to the significantly lead poisoned population were also offered on a prioritization basis, reaching only the cases with highest lead levels, due to limited staff. In late 1997, the program started planning for a different infrastructure on two fronts: how to deal with the limited inspection resources and how to improve the case management in the form of home visits offered to the lead poisoning cases in the state. The result of the conversations and strategizing became tangible in 1998 with two major factors: a) the prioritization of environmental inspections, and b) the establishment of the first "Lead Center".

In January 1998, the environmental inspections were privatized, and the RICLPPP started to refer initial inspections to a few private licensed inspectors who, under a fee and in compliance with the requirements of the contract and the Lead Poisoning Prevention Rules and Regulations, were asked to perform the inspections and submit the inspections reports to the Environmental Unit of the RICLPPP. The role of the inspectors in the Environmental Unit then turned to quality assurance and enforcement. Once the private inspector completes the initial inspection, the report is submitted to staff in the Environmental Unit for review, approval and payment. The technical assistance and contacts with the homeowner for lead hazard removal resources and eventually referral to enforcement agencies is still under the responsibility of the staff in the Environmental

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<sup>5</sup> "Managing Elevated Blood Lead Levels Among Young Children: Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention", March 2002, page 4.

Unit. Once the lead hazard removal work is completed, Environmental Unit staff also conducts the quality assurance and collection of clearance samples that eventually certify a unit as lead safe, according to Rhode Island's lead poisoning prevention regulations.

A similar strategy took place in the area of case management to families. There were months of dialogue and negotiation with the Rhode Island Department of Human Services, to establish a Lead Center whose primary role was to provide comprehensive case management and education to families of significantly lead poisoned children. After long negotiations and strategic planning with all relevant partners, the Medicaid agency issued certification standards that were open to qualified agencies to apply and become Lead Centers. The certification standards included several requirements and specific components in the areas of home visits, lead education, coordination of care with the medical provider, preventive cleaning and referral services, and established a billing methodology for reimbursement. Lead Centers then could receive referrals and were asked to submit a bill for opening a case, a monthly fee for each child under their care, and a closing fee as well, upon closing the case. The certification standards also included two levels of services: "Intensive" services for those cases in need of a variety of services, and "Maintenance" services for those that were in less serious conditions.

With the certification standards available, one Lead Center initiated operations in October of 1998, and started receiving referrals of significantly lead poisoned cases for the metropolitan area of Providence and surrounding cities. The remaining families that were not in the area served by the Lead Center continued to be referred to the Family Outreach Program for the same level of services that they were providing so far.

The first Lead Center opened services to serve the Medicaid/Rite Care eligible families and received a one-time grant from the RICLPPP to assess the need and seek funding to serve the non-Rite Care families. A couple of months after the establishment of the first Lead Center, in January 1999, the RI DHS approved the use of Medicaid funding to cover the cost of windows replacement, considered a medical need for those families who were Rite Care eligible, and had a significantly lead poisoned child.

While the windows replacement with Medicaid funding set a precedent and was widely recognized and promoted nationally, the operationalization of its implementation proved to be challenging and the process was more lengthy than initially anticipated.

Although the Lead Center established operations, the case management infrastructure was fragmented and the evaluation and quality of case management were a challenge given that there were two models of services that were unequally reimbursed, certified and had significant differences in approach. The RICLPPP, the Lead Center and Rhode Island DHS continued to work diligently in the evaluation and promoting quality for case management services provided to families, and in 2002 the RI DHS reviewed and reopened the certification standards to other agencies, in an effort to expand Lead Centers that could serve other areas in the state, thus making the case management approach one, unified, and equally reimbursed. Three additional agencies submitted proposals and were eventually certified by DHS, to begin services in January of 2003. With this new infrastructure of four Lead Centers, the referrals of significantly lead poisoned cases were distributed geographically by location of Lead Center. This fact also led to changes in the role of the Family Outreach Program, since all the cases that had previously been

referred to them now went to the Lead Centers. At that point, and after discussions with all partners, the RICLPPP started sending letters to families with children with first time lead levels of 10 to 14 mcg/dL encouraging them to contact the Family Outreach Program if they were interested in a home visit to learn how to protect their children from lead exposure.

Because of the Medicaid funding, Rhode Island DHS has maintained a contractual relationship with Lead Centers. Since the beginning, however, the relationship between RICLPPP and Lead Centers was based on a tacit agreement that RICLPPP would provide referrals and Lead Centers will offer services to families, but there was no document or tie that would hold parties to that agreement. Given this situation, a Memorandum of Understanding was prepared and signed by the parties in 2002 with the first Lead Center. Upon certification of the other Lead Centers, the MOU was updated and each one of them has now signed a MOU (appendix 9) that delineates the commitments that each party is making in this partnership, in terms of cooperation, quality assurance measures, site visits, technical assistance, data collection and evaluation, among others.

During 2002, when the state had two models for case management services, one with a Lead Center and another one with the Family Outreach Program, the RICLPPP convened a group with representatives of those agencies and started an evaluation of case management. The evaluation, which included data analysis and parental surveys, was completed and discussed with partners in early 2003.

The findings of the evaluation were discussed with the new group of Lead Centers, DHS and RICLPPP starting in early 2003. Although the findings of the evaluation involved different case management agencies and infrastructure, the new Lead Centers and every other member in the group agreed that it was important to address the identified issues and work jointly in a strategy that would form the foundation for quality. Since 2003, the group has been meeting on a monthly or bimonthly basis and has been taking all necessary steps to address any issues and resolve challenges as a group, with the technical assistance of the state agencies.

Another major factor took place in 2003, with the issuance of the CDC's guidance entitled "Managing Elevated Blood Lead Levels in Children". This new resource was made available to all the states and for the first time there was a real, concrete guidance related to handling case management of families with lead poisoned children. CDC also offered trainings in different locations, and held a training for Rhode Island in July of 2003.

RICLPPP invited all Lead Centers' staff as well as RI DHS to attend the training, which was highly successful. With this new tool as a resource, the group carefully reviewed and learned about the recommendations and put in place a number of strategies that were directed to assess and improve the quality of case management. Discussions among the group continued, and outcome measures were developed. The group decided it was important to measure how case management would be evaluated, and agreed on five outcome measures:

Coordination with medical care, through continuous contact between the lead centers and the child's PCP,

Parental education provided to the family, measured by a pre and post survey,

Nutrition and referrals, measured by access to the WIC program as well as success in the referrals to other services,

Developmental assessment, utilizing the "Ages and Stages Questionnaire" offered to all children under 36 months of age who haven't received such assessment yet, Housing referrals and results of them, including the success of environmental inspections completed, participation/application to lead hazard reduction resources, spot repairs and windows replacement completed in the unit.

With these outcome measures, there was a need to collect additional information and review forms, letters and standards that Lead Centers should put in place. The group agreed to modify a report to collect the data that can allow the evaluation of case management, and is currently implementing a web based report that Lead Centers can use to enter data for each closed case, and make these data accessible to RICLPPP for analysis and evaluation.

The group also felt it was important to have policies in writing so that all Lead Centers follow the same procedures. Since the formation of the group, many policies were discussed and put in place, and in 2005 the RICLPPP gathered those policies and compiled them in a book called the "Case Management Protocol" that is the basis for all efforts and steps that Lead Centers must follow for the provision of services. Additionally, RICLPPP participates in the site visits that RI DHS performs to Lead Centers to learn more about the Centers' performance and sees as an opportunity to provide technical assistance. So far, two site visits have been performed by the two state agencies to each Lead Center, in 2003 and in 2005.

Lead Centers continued operations and state agencies continued to provide support and technical assistance as needed. In late 2005, one of the Lead Centers withdrew its participation due to financial challenges in the agency primarily due to the few cases referred to their geographical area as well as the burden of non-Rite Care eligible families who required services and the lack of reimbursement for those cases. As of the beginning of 2006, there are three functional Lead Centers.

The facts presented above have been very important in the state as they have allowed formulating policies and providing an "out of the box" approach to case management. Most importantly, the changes in infrastructure have allowed the formulation of a strong group of partners who work jointly in quality assurance, technical assistance, training and overall the effort to improve case management for lead poisoned children and their families.

## 2. Current Activities and Intervention levels.

***Significant childhood lead poisoning<sup>6</sup> is a confirmed blood lead level greater than or equal to 20 mcg/dL in a child under six years of age. Alternatively, 2 samples from a child under six years of age, separated by at least 90 days but no more than 365 days, with a blood lead level greater than or equal to 15 mcg/dL shall also be deemed to constitute Significant Childhood Lead Poisoning.***

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<sup>6</sup> Rules and Regulations for Lead Poisoning Prevention, State of Rhode Island, Department of Health, [http://www.rules.state.ri.us/rules/released/pdf/DOH/DOH\\_3357.pdf](http://www.rules.state.ri.us/rules/released/pdf/DOH/DOH_3357.pdf)

The RICLPPP has a mechanism in place by which children with such lead levels are identified, referred to appropriate services and followed up. As stated previously, the state's law for lead screening and analysis of lead specimens is the starting point for the case management of lead poisoned children in Rhode Island. The State Laboratory analyzes lead screening specimens and sends a report to the provider and/or submitter. Lead screening data is therefore immediately collected in a database and daily reports are run to identify children's lead levels.

In July 2001, the blood lead intervention level was modified to include persistent lead levels of 15-19 µg/dL. RICLPPP defined a persistent lead level as two lead tests (venous or capillary) that are > 15 mcg/dL and at least ninety days apart but no more than 365 days apart (Rhode Island Department of Health Lead Screening and Referral Guidelines, March 2003). Children with persistent levels of lead poisoning received the same case management and environmental inspections defined above and 73 families were offered these services in 2004. In January 2006, the definition of a persistent case was changed to reflect venous tests of 15-19µg/dL only. This change was driven by the policy established in July 2004 to require venous confirmation of all capillary tests greater or equal to 10µ/dL and the change is not expected to significantly decrease the number of persistent referrals made each year.

Since 1999, RICLPPP also expanded case management services to "preventive" referrals for children with lead levels of 15-19 µg/dL. Children with blood lead levels of 15-19µg/dL are eligible to receive home visits and education from a Lead Center, however, an environmental inspection is not offered at this time. In 2004, 195 families were identified as eligible to receive a preventive referral. As of January 2006, preventive cases are also defined by a venous result only. This change occurred after recognizing that most parents refused services based on a capillary result of 15-19µg/dL and waited for venous confirmation before accepting lead center services.

This document includes a complete flowchart (appendix10) of the services provided to children depending on their lead levels. Following is a summary of procedures that depict the referral mechanism currently in place.

**a. For "significantly lead poisoned" children, the steps are as follows:**

1. The LESS database generates Provider Notification Letters on a daily basis for any children who are significantly lead poisoned. The letter notifies providers of lead levels of significantly lead poisoned children and identifies steps/recommendations.
2. The provider then is contacted by telephone and is asked to:
  - Inform the family/patient about the lead level, explain what the lead level means and what to expect next
  - Verify the patient's address
  - Notify the Department of Health if unable to contact the patient or if different information is found

3. A period of three days is allowed to ensure the provider has had time to communicate the findings to the patient. (The three-day period does not apply when the provider has already communicated results to the patient and for urgent lead poisoned cases.)
4. After the three days period, the referral form is completed and sent by fax to:
  - The primary care provider
  - The private inspector assigned to the address
  - The Lead Center assigned to the case

The information included in the Inspection Referral Form enables the primary care provider, the Lead Center and the private inspector to initiate contacts with the family for purposes of providing corresponding services.

The **primary care provider** is responsible for the medical follow up of the patient, and has the option to make a referral to one of the Lead Clinics at Hasbro Children's Hospital or Memorial Hospital (that see their own patients) or at St. Joseph's Lead Clinic.

The **private inspector** who receives the referral is responsible for contacting the family and scheduling a mutually agreed upon time to conduct the environmental inspection of the child's primary residence. Outcome of the contact is reported to the Division of Family Health within five working days to indicate any address changes, the date for which the inspection was scheduled, and/or any other circumstances that impede and/or allow scheduling the inspection.

The **Lead Center** provides comprehensive non-medical case management services, including conducting education to the family, and assisting the private inspector in the scheduling of the inspection, developing and implementing a family care plan. The Lead Centers help to address issues, coordinate care with the primary care provider, assist the family in the identification of lead hazard removal resources, provide window replacement and/or spot repair as needed, and provide overall support and referrals to the family.

The **Department of Health** sends an official notification to the homeowner with the findings of the environmental inspection, along with information for proper lead hazard reduction, resources and others. Further follow up and enforcement of non-compliant homeowners is the joint responsibility of the Department of Health and the Attorney General's Office. Once the inspection is completed, the report is prepared by the inspector and mailed to:

- The Department of Health
- The agency providing case management services,
- The parent

The number of services for lead poisoned children and the efficiency with which they are delivered have significantly increased and improved over the last few years in the state of Rhode Island. One significant improvement has to do with the environmental inspections. Years ago, the timeframe for the completion of environmental inspections in the homes of lead poisoned children was of several months. Since inspections were privatized in early 1998, that time has now decreased significantly, to somewhere between four to six weeks from the time the lead test result is available in the Lead Program's LESS database until the inspection is offered.

## **b. Other efforts to reach families of children with elevated blood lead levels**

In many cases, a child with a moderately elevated lead level is a likely candidate to become significantly lead poisoned in the near future, which can be prevented with family education and support. Past experience has proven the gain that can be made to further inform parents about lead poisoning. Although most parents are aware of the dangers of lead, only some are actively seeking help or using preventive measures, and efforts are continuously made to increase the level of awareness among parents of young children.

- **Home visit offered to parents of children with blood lead levels 10 to 14 mcg/dL**

One major achievement that has been made in the area of primary prevention has to do with the preventive lead education offered at no cost, to families of children with confirmed lead levels of 10 to 14  $\mu\text{g}/\text{dL}$ . This service started as a pilot project in March 1999, and consist of sending a letter that confirms the child has been tested for lead, provides basic information about the lead levels, how to interpret them, where to look for additional information, and encourages the parent to contact the Family Outreach Program (FOP) if they are interested in receiving a home visit. Emphasizing our efforts to communicate with more than the mainstream population, correspondence is sent in English and Spanish, covering about 95% of the audience.

The Family Outreach Program (FOP) has been providing similar services to thousands of families in the state. Several assessments, including newborn screening, developmental and metabolic screenings are provided by the FOP to families in their own homes, with professionals specialized in nursing and/or trained paraprofessionals such as Outreach and Family Workers to make complete family assessments and provide a full range of services and referrals.

At least two home visits are scheduled to educate the family about the dangers of lead. In the first visit a visual inspection is performed and a training to identify and reduce the child's exposure to potential lead hazards is provided. The visual inspection includes an assessment of the interior as well as the exterior of the house, and a practical demonstration of wet cleaning using a mix of water and a high phosphate cleaner (TSP). The family is also provided with necessary products (duct tape and a sample of the cleaner) to use as immediate preventive measures. There is also an effort to make referrals to other services, as needed, including lead-safe day care facilities, housing authorities and code enforcement units. A second visit is provided to the family to ensure that parents understood and have implemented temporary environmental lead hazard reduction measures. At this visit the FOP expert also emphasizes the importance of good nutritional practices and responds to any other questions. Within one month of the referral date, the FOP sends a report to the RI Department of Health, including the content of the visual assessment and the final outcome of the visits offered to the family.

Since its implementation in 1999, more than 1,400 families have been offered home visits to provide basic lead education and wet cleaning techniques. In 2004, 692 educational letters were sent to parents whose children have been lead tested and had confirmed results between 10 and 14  $\mu\text{g}/\text{dL}$ . Of these 692 families, 61 received a home visit from the FOP. The low response rate may be due to the action required by the parent to contact the FOP.

Experience suggests this outreach effort is adequate. It is not uncommon to receive calls from parents who have received our letter, asking questions, looking for clarification, making suggestions and/or in search of additional guidance. It has also become apparent that in many cases the note sent by RICLPPP is the first communication parents receive about the dangers of lead. Current plans are to continue with this outreach effort although some enhancements and expansion of the project can be considered in the future. In 2004, 755 educational cases were opened by RICLPPP. This number dropped to 435 educational cases in 2005.

- **Preventive referral to parents of children with venous blood lead levels 15 to 19 mcg/dL**

Since 2003, all results with a (venous or capillary) blood lead level 15 to 19 mcg/dL have been referred to Lead Centers for an in-home visit education and referral. In July 2004, with the modification of policy to confirm capillary tests, as well as due to the low capture rate that Lead Centers were experiencing in this group (parents were not accepting services until the child had a venous or confirmatory blood lead test), the referrals are only made if a venous test is within that range.

Lead Centers receive these referrals and offer a home visit, education and referral to these families, along with information on lead hazard reduction resources and spot repair. In 2003, 270 families were referred for preventive case management services. The number of preventive referrals 2004 and 2005 are 199 and 129, respectively.

### **3. Case Management Resources**

#### **a. Lead Centers**

One important milestone in the provision of case management services has to do with the establishment of the first Rhode Island Lead Center in October 1998. The "HELP Lead Safe Center" was founded to provide a full range of non-medical services to lead poisoned children and their families. In 2002, the Department of Human Services (DHS) re-issued the certification standards to ensure that services were accessible and truly statewide. In late 2002 DHS approved three new Lead Centers: Blackstone Valley Community Action Program, Family Service of RI, and Westbay Community Action Program. All four Lead Centers have signed an MOU with RICLPPP for purposes of receiving referrals, providing case management to significantly lead poisoned children under the Department of Health's guide, and working jointly on quality improvement efforts. The RI Department of Human Services provides Medicaid funding for services to the Medicaid/Rite Care eligible children, and there is currently no funding stream for the non-Medicaid group. However, Lead Centers have been providing services to both groups, indistinctive of funding.

In September of 2005, one lead center withdrew from providing case management services to families of lead poisoned children. This lead center terminated services because they experienced operating losses partially due to providing case management services to a large non-Medicaid population. Funding for providing services to non-Medicaid families has proven challenging for each lead center and the remaining 3 lead centers are exploring channels of

additional funding. In spite of the lack of funding, lead centers are still, but temporarily, providing case management services to non-Medicaid eligible families. Each lead center plans to approach the large Managed Care Organizations in RI to open discussions regarding insurance coverage for case management services to lead poisoned children.

### **b. Inspections**

Comprehensive environmental lead inspections (CELI's) provided as part of environmental case management for children who meet the Rhode Island definition of significantly lead poisoned (synonymous with EIBLL-Environmental Intervention Blood Lead Level) and for day care facilities licensed by the Department of Children, Youth and Families (DCYF). Under an agreement DOH has with DCYF the initial inspection for new facilities is provided by DOH to ensure that all facilities obtain lead safe certification prior to DCYF issuance of their license. Inspections to significantly lead poisoned children are conducted by a pool of private certified and licensed environmental lead inspectors since implementation of this initiative in 1998 that occurred due to staffing shortages in DOH's Environmental Lead Program. There are currently 11 inspectors who have elected to participate. This number has increased from the inception of the privatization program in direct relationship with the number of licensed lead inspectors. Inspectors are required to maintain Errors and Omissions Insurance, sign a DOH Confidentiality Form and apply for an EDS number for Medicaid reimbursement when applicable.

Currently, all inspectors providing this service must be associated with one of the six original lead inspection firms that signed the agreement in 1998. We have updated the original inspection agreements and plan to issue Request For Proposals in 2006 offering independent enrollment to all currently licensed inspectors that wish to participate.

Since implementing the private inspection process, the RICLPP have been able to expedite environmental interventions for significantly lead poisoned children with an average turn around time from identification, referral and inspection to approximately three to four weeks. As the amount of time necessary to conduct a CELI can run from 2 to 4 hours, privatizing has allowed the environmental staff of RICLPPP to timely conduct the enormous amount of follow-up needed for a property to achieve lead safe certification including: site consultations with owners/agents/realtors/prospective buyers etc., appropriate documentation of activities in hard copy files and the Lead Elimination Surveillance System (LESS), surveillance of the property to ensure work is conducted in accordance with regulation, posting and preparing non-compliant cases for court and court re-inspections, testimony, clearances/sample collection and issuance of lead safe certification.

### **c. Medicaid Funding For Windows Replacement And Spot Repair**

In addition to providing Medicaid funding for comprehensive non-medical case management through Lead Centers, Rhode Island DHS became the first Medicaid agency that obtained approval to utilize Medicaid funds for the replacement of windows in the homes of Medicaid eligible lead poisoned children. Here it is a chronology of DHS involvement in the formulation and implementation of such strategy.

FALL 1996—Staff at DHS became aware that RItE Care children with lead poisoning were frequently re-exposed to lead due to lack of affordable, lead safe housing in certain areas of Rhode Island, especially urban inner cities.

1997—DHS analyzed all services provided to children with lead poisoning. The decision was made to create a new provider type "certified lead center" which would provide comprehensive services to lead poisoned children, including case management and window replacement. All Medicaid children with a venous blood lead level greater than 20 µg/dL or a persistent 15 µg/dL would be eligible for the case management service under a pre-existing targeted case management group. Permission would be sought from HCFA to provide window replacement as an additional benefit under Rhode Island's RItE Care waiver. Children with a single venous blood lead level of 15 to 19 µg/dL would receive the same case management services from a certified lead center, however, they would not be offered a comprehensive environmental inspection.

JANUARY TO JUNE 1998—Workgroup established with staff from Center for Child and Family Health at the Department of Human Services and staff from Department of Health to develop certification standards for lead centers.

JUNE 1998—Letter sent to HCFA requesting permission to include window replacement as a RItE Care benefit.

JULY 1998—Certification standards for lead centers released; advertisement placed in Providence Newspaper seeking qualified providers.

AUGUST 1998—DHS certifies first lead center.

OCTOBER 1998—The first Lead Center opens.

DECEMBER 1998—DHS receives HCFA approval for window replacement as a RItE Care benefit.

JANUARY 1999—DHS and Lead Center meeting to operationalize window replacement benefit.

FEBRUARY 1999-APRIL 2000—Legal staff from DHS and Rhode Island Housing and Mortgage Corporation meet to develop a unified lien for properties receiving abatement, including Medicaid-funded window replacement.

JUNE 2000— First windows replaced in home of lead poisoned child.

AUGUST 2000—Press conference announcing window replacement program for lead-contaminated houses and new money for lead abatement.

JANUARY 2004—Three additional lead centers are certified to provide non-medical case management to lead poisoned children

OCTOBER 2005— One lead center discontinues operations. Three lead centers are receiving all referrals.

Rhode Island's window replacement program has been successful but its implementation has been slower than anticipated. Although all of the factors that contributed to this delay are not fully understood, it may be related at least in part to the initial delay in the lead centers' developing expertise in the technical details involved in window replacement. Following the receipt of technical assistance, the lead centers have demonstrated greater comfort with the processes surrounding window replacement.

Also, the number of housing units that have received window replacements funded by Medicaid has been less than initially projected. Several reasons for this difference have been identified. Families must plan to remain in the housing unit in order for DHS to approve the use of Medicaid funds to pay for window replacement. Some families are reticent to stay in housing when their

child has sustained an elevated lead level. Another reason pertains to the reluctance of some property owners to have a lien placed on the title to their property, as required for Medicaid funding. Thus, some property owners elect to pay directly for window replacement. In other situations, property owners are able to identify and access alternative sources of funding. If no other funding sources are available, Medicaid serves as the "payer of last resort". Therefore, the actual volume of window replacements that have occurred due to the intervention of the lead centers is higher than the number paid for with Medicaid funds.

#### 4. Enforcement

The Rhode Island Lead Poisoning Prevention Regulations [R23-24.6PB] have contained Lead Hazard Reduction Standards since 1993 and were amended in 1999 to include the Lead Hazard Control Standard (Section 14.0) for housing that has not been identified as the residence of a significantly lead poisoned child that meets the criteria set forth by EPA. All regulated facilities and residences that have significantly lead poisoned children under the age of six years old must utilize lead hazard reduction where applicable and obtain lead safe certification after abatement and dust wipe testing. All other applicable regulated residential facilities must utilize lead hazard controls to ensure lead safe work practices that include dust wipe testing and issuance of a *Certificate of Acceptable Dust Clearance* by a certified lead professional at the conclusion of the remediation.

Individuals who conduct this type of work must be properly trained by attendance to a RICLPPP Approved and licensed 8-hour Lead Safe Remodeler/Renovator training provider course and a remodeler/renovator license must be obtained from the RICLPPP Environmental Lead Program. EPA does not currently require licensure for this. However RI statute dictates that all lead professionals must have approved training and licensure. RI is at the fore-front for this level of lead hazard control as the EPA Remodeler/Renovator Rule coming out in early 2006 is expected to create tighter training, licensure and work oversight that RI already has in place.

The Housing Resources Commission (HRC) also adopted into their Lead Hazard Mitigation Regulation the requirement that Lead Hazard Control under their jurisdiction be conducted by DOH licensed Remodeler/Renovator to ensure that remediation over the de minimus is conducted safely. All rental properties not otherwise exempted that do not have a significantly lead poisoned child must remediate lead hazards and obtain dust wipe testing and Certificates of Conformance. DOH and HRC jointly collaborate in issuance of policy, guidelines and oversight of the licensed community under HRC jurisdiction as all lead professionals are licensed, certified and monitored by the Environmental Lead Program Unit of RICLPPP under a cooperative agreement with the Environmental Protection Agency, Region I.

The Department of Attorney General has created and promulgated Guidelines to Prevent Retaliatory Eviction in June 2004, as mandated in Rhode Island General Laws § 23-24.6-23(c) (4). These guidelines are available on-line at the Rhode Island Secretary of State website. RICLPPP works in coordination with child advocacy groups and the Lead Centers to provide guidance and refer tenants who experience illegal eviction to Rhode Island Legal Services.

Environmental inspection reports for the properties that have received a CELI for an EIBLL child are routinely shared with the HUD funded lead hazard reduction programs at their request. We

similarly provide this environmental report to local minimum housing agencies, and federal agencies that are in need of this data for surveillance and enforcement purposes. The RICLPPP has an ongoing working relationship with EPA Region I Office of Environmental Stewardship as a component of the Rhode Island TSCA grant cooperative agreement goal to investigate an MOU with EPA and provide assistance and environmental data in their investigations of 1018 violators within the state of RI. The Environmental Lead Unit conducts site assessments, provides ownership/property data, presents testimony in Superior Court and shares blood lead information with EPA in order to enhance the Office of Environmental Stewardship case against violators. There have recently been several non-compliant very large rental property owners obtaining lead safe certification for all of their properties regardless of whether that property was one of those in violation thus leading to a substantial increase in the availability of lead safe housing. RICLPPP also shares environmental data with the local Housing Authority Section 8 Offices under an MOU to ensure that all eligible tenants are residing in lead safe housing.

Unit data submitted to RICLPPP by the Authorities is matched by via addresses and the resulting matches are shared with the Housing Authorities. The Housing Authorities have also been advised to routinely check the RICLPPP website that list properties that meet the Lead Poisoning Prevention Act, as amended, definition of High Risk, Multiple Poisoning and On-Going Violation (those having received a 2<sup>nd</sup> Notice of Violation) in order to enhance their monitoring capabilities.

## **5. Quality Assurance Activities**

With the addition of 3 new lead centers in January 2003, RICLPPP identified the need to bring managers of the centers together on a regular basis to share knowledge and offer technical assistance to the newer lead centers. This group agreed to work on several quality assurance efforts that were discussed in the Case Management Evaluation (appendix 11). Lead Centers, RICLPPP and DHS continue to meet monthly, as needed. Each party participates in the agenda design and this forum is helpful for lead centers to ask for assistance when needed. In December 2005, HEALTH implemented the web based data entry system to collect additional data from each lead center upon closing a case. This data will include all lead poisoning cases that have been opened since January 2004 and will provide the source for additional analyses and evaluation of case management services.

RICLPPP and DHS performed site visits at the 3 remaining Lead Centers in the fall of 2005. Findings and recommendations will be shared with each lead center and an action plan is being developed by RICLPPP for issues and suggestions for improvements that were identified during the site visits. Lead centers have expressed the need for additional training of staff upon turnover or hiring new employees. RICLPPP will work with DHS to provide one on one training for case managers and to coordinate additional trainings on such topics as the Ages & Stages developmental screening tool. In addition to these trainings, in June of 2005 RICLPPP developed and distributed a Case Management Protocol (appendix 12) intended to be used as a single source of information for policies, correspondence, quality assurance efforts and available reports.

The Case Management Protocol has proven to be a valuable tool for existing and new staff and RICLPPP continues to update the protocol as necessary. The protocol will be used as a training tool and a reference guide moving forward.

## 6. Evaluation and Outcome Measures

An evaluation of child case management services was completed in January 2003. As a result of this evaluation, we developed the following outcome measures:

- Percent change in score on a parental pre/post test to assess knowledge of lead
- Rate of change of blood lead levels before and after case management
- Rate of screening among siblings of children with elevated blood lead levels
- Percent of children in WIC before and after case management
- Percent of children with completed Ages and Stages Questionnaires (ASQ)
- Percent of children enrolled in Early Intervention (EI) before and after case management
- Percent of children that are referred to other services
- Percent of families who receive spot repair/window replacement
- Percent of families who accept an inspection when offered
- Number of successful lead hazard reduction applications

In order to collect data necessary to assess the outcome measures, we developed a pre- and post- test to evaluate parental knowledge of lead, and re-designed the closed case report so we could collect additional relevant information. A web-based data entry system is being designed to collect and store the data from the closed case reports since January 1, 2004. After all the data are entered, analyses will be conducted on the outcome measures listed above. Another evaluation is scheduled for 2006.

An evaluation to assess the effectiveness of environmental inspections is in the planning process, and is planned to be conducted in 2006. The two major questions of interest are:

1. What is the rate of future poisonings at units that were not offered an inspection (pre-1978 housing not qualifying for an inspection), compared to units where:

- An inspection was offered, performed and hazards were abated
- An inspection was offered, performed and hazards were not abated
- An inspection was offered and not performed
- An inspection was (should have been) offered but the unit is no longer regulated

2. What is the trend in children's blood lead levels when an inspection is refused compared to children's blood lead levels when an inspection is performed and hazards are abated?

Categories to compare:

- Inspection refused and case management services refused
- Inspection refused and case management services accepted
- Inspection accepted and case management services refused
- Inspection accepted and case management services accepted

RICLPPP recognizes that while evaluation of this program component is a priority, significant resources must be available to conduct a thorough assessment. The program has made efforts to allocate resources, including the hiring of an intern who conducted important data collection and

cleanup in the summer of 2005 that was a preliminary step in the data analysis needed for this evaluation. Subsequent steps on this direction will be taken in the remaining part of 2006.

## **7. An Outlook to the Future**

Rhode Island has made significant achievements in the area of case management in the last few years, such as the increased and improved infrastructure of lead centers, partnerships formed with the Attorney General's Office and others for enforcement, and the ability to utilize Medicaid funding for window replacement and spot repairs. Furthermore, Lead Centers have signed MOUs with RICLPPP and this solid partnership has greatly facilitated the joint efforts in the area of quality assurance, including the formulation of outcome measures, also aided by the improved surveillance system that allows additional data collection.

The program is committed to investing resources and putting effort into case management. Specifically, the program is planning the following areas of work in the near future:

- Continuing the work with the Lead Centers and RI DHS in the quality improvement activities, and formulating an evaluation of the case management impact utilizing the established outcome measures,
- Providing ongoing training, site visits and technical assistance to Lead Centers,
- Continuing the work to conduct the evaluation of environmental case management,
- Working on the implementation of the EPA Remodeler/Renovator Rule expected to be issued in 2006,
- Reviewing the agreement for private inspections and issuing a Request for Proposal (RFP) to expand the network of licensed inspectors serving the significantly lead poisoned population,
- Assisting the Lead Centers in the identification of funding for the non-Medicaid population,
- Working with Lead Centers in the operationalization and improvement of the window replacement and spot repair programs.

## **SECTION V. EDUCATIONAL STRATEGIES**

To compliment the RICLPPP's screening and case management strategies, a number of education and outreach efforts are undertaken to inform stakeholders such as parents, providers and legislators of the importance of screening and case management. A summary of these activities is provided below.

### **1. Lead Month**

May is "Lead Poisoning Prevention Month" in Rhode Island. Each year, RICLPPP utilizes the month of May as an opportunity to conduct mass outreach to families with young children in Rhode Island. In 2005, this effort included informational pamphlets that highlighted the importance of screening and were distributed to over 4,500 families through elementary schools in the state. The RICLPPP also utilized Lead Poisoning Prevention Month as a way to promote screening among medical providers. Providers that have regularly utilized the state's integrated child health database, KIDSNET, to identify children in the practice that are in need of a lead screening are honored at the RICLPPP annual awards event, as well as through the KIDSNET and RICLPPP newsletters.

### **2. Outreach to providers**

Outreach to providers is achieved through a variety of methods. Provider relations staff with the KIDSNET program promote the use of the "unscreened reports" when enrolling practices or providing technical assistance or trainings to any pediatric practice. Additionally, the RICLPPP staff regularly promotes the RI Lead Screening and Referral Guidelines and offer trainings to any providers that would like additional, information. Third and fourth year medical students and newly licensed providers in the state are sent a "Welcome packet" that provides information on screening guidelines. Finally, the RICLPPP works closely with the Rhode Island College School of Nursing and provides informational sessions and trainings with students in the Community Health Nursing track during each of 3 semesters (fall, spring, and summer) each year. The importance of screening and the Lead Screening and Referral Guidelines are highlighted during these trainings.

### **3. Outreach to Schools, Daycares, and Social Service Agencies**

The RICLPPP receives regular requests from agencies working with families with young children for staff training on lead poisoning prevention. The RICLPPP utilizes these trainings as an opportunity to staff of the resources available for families, and to stress the importance of lead screening for children under the age of six.

### **4. Mailings to families**

The RICLPPP works to ensure that all children in Rhode Island receive one lead screening by 18 months of age. As part of this effort, the RICLPPP sends educational materials and a letter to families with children that have not been screened for lead poisoning by the time they turn 18 months of age.

## **5. “Keep It Clean” campaign**

The “Keep It clean” campaign is dedicated to eliminating lead poisoning in children and adults as the result of home improvement projects. By educating the consumer through customer interaction, it aims to spread the word on how to conduct lead-safe work in the home. The core of the campaign is a set of partnerships with local contacts from the “Keep It Clean” campaign (Lead Program staff) and local hardware and paint stores, where families already go to receive “how to” information and to purchase materials.

## **6. Parent Consultant**

With the goal of bringing the consumer (parents) perspective to the program, the Childhood Lead Poisoning Prevention Program works with a bilingual Parent Consultant who acts as the liaison to parents, and participates in community presentations, direct outreach, and peer education. The Parent Consultant maintains a constant presence at many community events, such as health fairs, to promote the importance of screening.

## **7. “Lead Update”**

The bimonthly publication is distributed by fax and mail to medical providers (pediatricians and family practitioners), community-based agencies, childcare providers and schools. It contains the latest information on the program’s new efforts, research findings, policies, statistics, quality assurance efforts, upcoming events and other field related issues. The Lead Update, and all past issues, are also included on the RICLPPP website.

## **8. Web Page**

The Lead Program’s web page is another mechanism to bring information to our constituencies. It is being updated continuously and contains the last three to four years of lead poisoning data, past editions of the “Lead Update” as well as the Program’s Rules and Regulations. It also offers a way to obtain educational brochures (in English and Spanish), and how to contact the RICLPPP. Through our website, providers are able to access the Lead Screening and Referral Guidelines, and families are able to contact licensed lead inspectors and the three certified lead centers in the state.

## **9. Educational Materials**

A variety of educational materials are available to parents, professionals and health care providers, with information about screening, prevention measures, the importance of nutrition on children and pregnant women, the sources of lead and ways to prevent lead poisoning, among others. All materials are available in large and small quantities and are free of charge.

## **10. Toll free line: 1-800-942-7434.**

Recognizing that a public information need continues to exist and having in mind a customer satisfaction overall approach, the toll free line is available Monday through Friday and has bilingual (English/Spanish) capacity. The Family Health Information Line staff responds to

questions related to lead poisoning and other programs for families with young children, provides referrals to other services and serves as the first friendly point of contact between the public and the Department.

## **11. An Outlook to the Future**

The RICLPPP will continue to coordinate its primary and secondary prevention strategies in an integrated manner as we move forward in eliminating childhood lead poisoning from Rhode Island communities. The RICLPPP will continue to target parents and providers to stress the importance of lead screening as a critical tool in the detection and management of childhood lead poisoning in Rhode Island.

The program will continue to work on specific initiatives in the coming years to target high risk groups, including, but not limited to:

- Working with the Refugee Health Program and Refugee Health Educators to ensure lead poisoning education for refugees and ensure screening and follow-up for all refugee children under the age of 16.
- Targeting school districts in the six core cities during Lead Poisoning Prevention Month outreach activities to reach out to families in these high-risk communities.
- Capitalizing on the strengths of the KIDSNET system to outreach to families and providers to stress the importance of timely lead screenings.
- Maintaining the current level of educational and outreach strategies for a variety of audiences, with special emphasis on educating homeowners and tenants for the maintenance and improvement of their housing conditions.

## **SECTION VI. APPENDICES**

1. Rhode Island Childhood Lead Poisoning Prevention Advisory Committee
2. Rhode Island Lead Screening Strategies
3. Rhode Island EPSDT Periodicity Schedule
4. Managed Care Organization Memorandum of Understanding
5. Parent Reminder Letter for Unscreened Child at 15 Months
6. Lead Screening and Referral Guidelines for Refugee Children
7. Distribution of Rhode Island Children Screened Once by 18 Months of Age
8. Policy for Lead Screening Specimen Analysis
9. Lead Center Memorandum of Understanding
10. Interventions Offered by Blood Lead Level- Flow Chart
11. Case Management Evaluation

**APPENDIX 1**

**Rhode Island Childhood Lead Poisoning Prevention Advisory  
Committee**

## Rhode Island Childhood Lead Poisoning Prevention Advisory Committee

| First Name  | Last Name      | Agency   |
|-------------|----------------|--|
| Rita        | Boie           | Comprehensive Child Care Services Network of RI            |
| Frank       | Bragantin      | Ferland Corporation  |
| Dawn        | Britto         | Early Head Start   |
| Robert      | Burke          | Memorial Hospital  |
| Nolan       | Byrne          | Department of Human Services                               |
| Kristine    | Campagna       | VNA Care of New England                                    |
| Maria       | Chionchio      | Children's Friend and Service                              |
| Patrice     | Cooper         | United Healthcare  |
| Gilson      | DaSilva        | Blue Cross Blue Shield of RI                               |
| Doris       | DeLosSantos    | Rhode Island Housing                                       |
| Christopher | Dillon         | City of Providence Code Enforcement                        |
| Paula       | Dunne          | Westbay Community Action Program                           |
| Dorothy     | Ericksson      | Neighborhood Health Plan of RI                             |
| Helena      | Friedmann      | Childhood Lead Action Project                              |
| Jeanne      | Gibree         | United Healthcare of New England                           |
| Chris       | Gorham         | Rhode Island Housing                                       |
| Lynda       | Greene         | Providence Community Centers                               |
| Lisa        | Holland        | United Healthcare of New England                           |
| Dave        | Johnston       | City of Providence, Department of Planning and Development |
| Sharon      | Kernan         | Department of Human Services                               |
| Ann         | Kinneavy       | Rhode Island Hospital Lead Clinic                          |
| Heather     | Kinsey         | Westbay Community Action Program                           |
| Simon       | Kue            | Housing Resources Commission                               |
| John        | Logan          | Brown University   |
| Christina   | Londono        | Family Service of RI                                       |
| Leslie      | Martineau      | Lady of Fatima Hospital                                    |
| Jan         | Moore          | Blackstone Valley CAP                                      |
| Christine   | Paccia         | Coordinated Health Partners                                |
| Virginia    | Paine          | Woonsocket Head Start                                      |
| Suzy        | Paiva          | St. Joseph Health Services                                 |
| Ita         | Principe       | Rhode Island Housing                                       |
| Robyn       | Riley          | Child Inc.   |
| Carol       | Schraeder      | Warwick Lead Hazard Reduction Program                      |
| Mary        | Schreitmueller | Child Inc.   |
| Noreen      | Shawcross      | Rhode Island Office of Housing and Community Development   |
| Diane       | Shemtov        | Family Service of Rhode Island                             |
| Monica      | Staaf          | RI Association of Realtors                                 |
| Donna       | Tattari        | Providence Head Start                                      |
| June        | Tourangeau     | St. Joseph Hospital Lead Clinic                            |
| David       | Ubiera         | St. Joseph Hospital-Laboratory                             |
| Patrick     | Vivier         | Rhode Island Hospital                                      |

**APPENDIX 2**

**Rhode Island Lead Screening Strategies**

**LEAD SCREENING QUALITY ASSURANCE EFFORTS**  
**RI Childhood Lead Poisoning Prevention Program**  
**February 2006**

| <u>APPROACH TYPE</u>   | <u>POPULATION</u>   | <u>FREQUENCY</u>  | <u>METHOD</u>   | <u>FEEDBACK/<br/>NEXT STEPS</u>   |
|--|---|---|---|---|
| <b>1. Parent Approach</b> Post cards sent to all children turning 12 months of age<br><u>Source: KIDSNET</u>   | All children born in Rhode Island turning one year of age   | Report, Labels and mailing conducted weekly                                 | Reminder Post Cards mailed to Parents to have their children screened at their upcoming 12 Month Well-Child Visit                                 | Re-send cards to any new addresses. Update KIDSNET with new addresses   |
| <b>2. Parent Approach</b> Letter sent to parents of unscreened 18-month old children<br><u>Source: KIDSNET</u>   | All children active in KIDSNET turning 18 months of age   | Report, Labels and mailings conducted monthly                               | Letter sent to Parents (with other educational materials) encouraging them to have their children screened at upcoming 18 Month Well-Child Visit. | Re-send letters to any new address. Update KIDSNET with new addresses   |
| <b>3. Provider Approach</b><br>Providers use of KIDSNET's report of patients never screened<br><u>Source: KIDSNET</u>  | All KIDSNET participating pediatric providers seeing patients born since 1/1/97                           | Providers can run the report on demand. Monitoring is done by CLPPP monthly | RICLPPP reviews the KIDSNET web usage report monthly  | Usage of the reports is published in the KIDSNET newsletter monthly. Frequent (providers) users are recognized at annual Lead Month Event users |
| <b>4. WIC approach</b><br>Report generated from KIDSNET<br><u>Source: KIDSNET</u>  | Active children under the age of 5 with no lead test  | Conducted as often as WIC agencies can conduct QA                           | A report is generated from KIDSNET and sent to the WIC Program's Coordinators for review and follow up  | N/A   |
| <b>5. MCOs approach</b><br>Data matched with lead screening data in LESS<br><u>Source: LESS and MCOs data</u>  | Children turning 24 month old enrolled in one of the 3 MCOs in RI without a claim for lead screening test | Twice a year, in the Fall and in the Spring                                 | MCOs data is matched with lead screening data in LESS; the lead screening rate for the population is calculated                                   | List of unscreened children is reported to each MCO; total screening rate is reported to Medicaid agency  |
| <b>6. Annual Immunizations School Survey</b><br><u>Source: Reports collected at site visits by the Immunizations Program</u><br><u>Source: Schools records</u> | All children under six enrolled in a school setting   | Annually  | Survey completed by Schools (required and sent by the Immunizations Program)  | Analyze the data and prepare a report   |
| <b>7. Refugee effort</b><br>Refugee data matched with data in LESS<br><u>Source: Refugee and LESS data</u>   | All refugee entering the state of RI as reported to the State's Refugee Program                           | Quarterly or as often as Refugee data is made available to RI CLPPP         | Lookup in the database to identify (refugee) children unscreened and/or in need of follow up lead screening                                       | Follow up via the provider  |

**APPENDIX 3**

**Rhode Island EPSDT Periodicity Schedule**

RHODE ISLAND EPSDT PERIODICITY SCHEDULE

| PROCEDURE                                  | Infancy |                  |      |      |                  |                |                  | Early Childhood  |                  |                |         |                | Middle Childhood |                  |                |                | Adolescence     |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
|--|---------|------------------|------|------|------------------|----------------|------------------|------------------|------------------|----------------|---------|----------------|------------------|------------------|----------------|----------------|-----------------|-----------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|-----------------|
|  | NB*     | By 1 Mo          | 2 Mo | 4 Mo | 6 Mo             | 9 Mo           | 12 Mo            | 15 Mo            | 18 Mo            | 24 Mo          | 30 Mo** | 36 Mo          | 4 Yrs            | 5 Yrs            | 6 Yrs          | 8 Yrs          | 10 Yrs          | 11 Yrs          | 12 Yrs           | 13 Yrs           | 14 Yrs           | 15 Yrs           | 16 Yrs           | 17 Yrs           | 18 Yrs           | 19 Yrs           | 20+ Yrs         |
| History (Initial/Interval)                 | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Height                                     | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Weight                                     | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Head Circumference                         | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         |                |                  |                  |                |                |                 |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
| Blood Pressure                             |         |                  |      |      |                  |                |                  |                  |                  |                |         |                | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Physical Exam (unclothed)                  | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Developmental/Behavioral/Language/Speech   | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Anticipatory Guidance <sup>1</sup>         | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Vision/Sight Screen                        | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | (x)            | x               | x               | (x)              | x                | x                | x                | (x)              | x                | x                | x                | (x)             |
| Hearing Screening - Subjective             | x       | x                | x    | x    | x                | x              | x                | x                | x                | x              |         | x              | x                | x                | x              | x              | x               | x               | x                | x                | x                | x                | x                | x                | x                | x                | x               |
| Hearing Screening - Objective <sup>2</sup> | x       |                  |      |      |                  |                |                  |                  |                  |                |         | x <sup>2</sup> | (x) <sup>2</sup> | (x) <sup>2</sup> |                |                |                 |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
| Immunization <sup>3</sup>                  |         |                  |      |      |                  |                |                  |                  |                  |                |         |                |                  |                  |                |                |                 |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
| Hemoglobin/Hematocrit <sup>4</sup>         |         |                  |      |      | x                | (x)            | (x)              |                  |                  |                |         | x <sup>4</sup> | x <sup>4</sup>   |                  |                |                |                 | x <sup>4</sup>  | (x) <sup>4</sup> | (x) <sup>4</sup> | (x) <sup>4</sup> | (x) <sup>4</sup> | (x) <sup>4</sup> | (x) <sup>4</sup> | (x) <sup>4</sup> | (x) <sup>4</sup> |                 |
| Urinalysis <sup>5</sup>                    |         |                  |      |      |                  |                |                  |                  |                  |                |         |                |                  |                  |                |                |                 |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
| Blood Lead Screening <sup>6</sup>          |         |                  |      |      |                  | x <sup>6</sup> | (x) <sup>6</sup> | (x) <sup>6</sup> | (x) <sup>6</sup> | x <sup>6</sup> |         | x <sup>6</sup> | x <sup>6</sup>   | x <sup>6</sup>   | x <sup>6</sup> |                |                 |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
| Hereditary/Metabolic Screen <sup>7</sup>   | x       | (x) <sup>7</sup> |      |      | (x) <sup>7</sup> |                |                  |                  |                  |                |         |                |                  |                  |                |                |                 |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
| Dental <sup>8</sup>                        |         |                  |      |      |                  |                |                  |                  |                  |                |         | x <sup>8</sup> | x <sup>8</sup>   | x <sup>8</sup>   | x <sup>8</sup> | x <sup>8</sup> | x <sup>8</sup>  | x <sup>8</sup>  | x <sup>8</sup>   | x <sup>8</sup>   | x <sup>8</sup>   | x <sup>8</sup>   | x <sup>8</sup>   | x <sup>8</sup>   | x <sup>8</sup>   | x <sup>8</sup>   |                 |
| PPD <sup>9</sup>                           |         |                  |      |      |                  |                |                  | x <sup>9</sup>   |                  |                |         | x <sup>9</sup> | (x) <sup>9</sup> |                  |                |                |                 |                 |                  |                  |                  |                  |                  |                  |                  |                  |                 |
| Sexual history <sup>10</sup>               |         |                  |      |      |                  |                |                  |                  |                  |                |         |                |                  |                  |                |                | x <sup>10</sup> | x <sup>10</sup> | x <sup>10</sup>  | x <sup>10</sup>  | x <sup>10</sup>  | x <sup>10</sup>  | x <sup>10</sup>  | x <sup>10</sup>  | x <sup>10</sup>  | x <sup>10</sup>  | x <sup>10</sup> |

Notes

- x Do at this age
- (x) Do at this age unless previously done at scheduled age
- \*\* Optional, if earlier visits warrant closer follow-up
- NB - Newborn exam done in the hospital or at two to three days
- <sup>1</sup> Anticipatory Guidance refers to age-appropriate guidance to parents, children, and adolescents on: injury and illness prevention; developmental surveillance and milestones; sexuality, substance abuse; etc. Refer to publications such as: *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents* (USPHS); *Guide to Clinical Preventive Services* (USPHS); *Guidelines for Adolescent Preventive Services* (AMA)
- <sup>2</sup> Once during three to five age group, a simple audiometric hearing test must be performed

- 3 Follow most recent schedule recommended by Advisory Committee on Immunization Practices (ACIP)
- 4 Do at this age if at risk of nutritional anemia; do for all menstruating adolescents
- 5 Do only when indicated clinically
- 6 Screen annually between 9 months and 6 years of age.
- 7 Refers to metabolic screening if newborn result not known, or testing not done in newborn period, for at-risk groups
- 8 All children ages three and older must be referred directly to a dentist for screening annually as part of EPSDT exam
- 9 Do for individuals at risk
- 10 Include STD screen/pelvic exam as indicate

## LEAD SCREENING REQUIREMENT PER RHODE ISLAND LAW/DEPARTMENT OF HEALTH REGULATION

All children in Rhode Island shall be screened for blood lead in accordance with the following schedule:

- (a) Each child between nine (9) and thirty-six (36) months of age shall be screened for blood lead at least annually. More frequent blood lead screening of asymptomatic children less than thirty-six (36) months of age may be justified based on the child's residence, the quality of the housing where the child resides, and the prevalence of lead poisoning in the child's neighborhood.
- (b) Each child between thirty-seven (37) and seventy-two (72) months of age shall be screened for blood lead annually, except as provided for in line (e) below.
- (c) Children who are developmentally delayed shall receive blood lead screening tests at intervals appropriate for their developmental age.
- (d) Children exhibiting signs or symptoms consistent with lead poisoning (unusual loss of appetite, abdominal pain, or constipation; ingestion of non-food items (pica); seizures without fever; loss of developmental milestones or unusual changes in behavior) shall have an appropriate diagnostic evaluation, including a venous sample for blood lead determination, and shall not be considered appropriate candidates for a blood lead screening test.
- (e) **Discontinuance of Annual Blood Lead Screening.** Annual blood lead screening for each child between thirty-seven (37) and seventy-two (72) months of age may be discontinued under the following circumstances:
  - (1) All of the child's blood lead screening tests conducted during the first thirty-six (36) months of life were less than fifteen micrograms of lead per deciliter of whole blood; **and**
  - (2) The child's first blood lead screening test conducted between thirty-seven (37) and seventy-two (72) months of age was less than fifteen; **and**
  - (3) The child has not moved to another residence; **and**
  - (4) The child's residence has not undergone any change which may pose a lead hazard. Such changes include, but are not limited to, sandblasting of a neighbor's house or renovation of the child's home involving generation of lead-contaminated dust; **or**
  - (5) The child reaches seventy-two (72) months of age.
- (f) Notwithstanding the requirements of Paragraphs A.2.1(a) and (b) of these regulations, blood lead screening shall not be conducted if the parents of the child object to such screening on the grounds that it conflicts with their religious tenets and practices.

**APPENDIX 4**

**Managed Care Organization Memorandum of Understanding**

INTER-AGENCY DATA SHARING AGREEMENT  
BETWEEN  
THE RHODE ISLAND DEPARTMENT OF HEALTH  
THE RHODE ISLAND DEPARTMENT OF HUMAN SERVICES,  
BLUE CROSS & BLUE SHIELD OF RHODE ISLAND,  
NEIGHBORHOOD HEALTH PLAN OF RHODE ISLAND,  
AND UNITEDHEALTHCARE OF NEW ENGLAND, INC.

**I. AGENCY CONTACTS**

RI Department of Health  
Childhood Lead Poisoning Prevention Program  
Magaly C. Angeloni  
3 Capitol Hill  
Providence, RI 02908-5078  
401-222-4602, email [magalya@doh.state.ri.us](mailto:magalya@doh.state.ri.us)

RI Department of Human Services  
Center for Child and Family Health  
Nolan Bryne Simpson  
600 New London Avenue, Cranston, RI 02920  
401-462-2489, email [nbyrne@dhs.ri.gov](mailto:nbyrne@dhs.ri.gov)

Blue Cross & Blue Shield of Rhode Island  
Gilson F. DaSilva  
Product Manager - RlTe Care  
One Empire Plaza, 2<sup>nd</sup> floor Providence, RI 02903-3279  
401-459-1738, email [dasilva.g@bcbsri.org](mailto:dasilva.g@bcbsri.org)

Neighborhood Health Plan of Rhode Island  
Dorothy Erickson  
299 Promenade Street  
Providence, RI 02908  
401-459-6127, email [derickson@nhpri.org](mailto:derickson@nhpri.org)

UnitedHealthcare of New England, Inc.  
Patrice Cooper  
Executive Director  
475 Kilvert Street  
Warwick, RI 02886  
401-732-7439, email [pcooper@uhc.com](mailto:pcooper@uhc.com)

**II. PURPOSE**

WHEREAS the mission of HEALTH's Childhood Lead Poisoning Prevention Program is to "prevent childhood lead exposure and poisoning," by ensuring children are lead screened;

WHEREAS, the RHODE ISLAND DEPARTMENT OF HEALTH, through its Childhood Lead Poisoning Prevention Program maintains an electronic database with blood lead data of RI children under six years of age who have been screened;

WHEREAS, the RHODE ISLAND DEPARTMENT OF HUMAN SERVICES (DHS) is responsible for the Administration of the Medical Assistance program in accordance with RIGL 40-8-1 et seq.; 40-8-13; 42-12.3-1 et seq.; and 40-5.1-19; 40-8.4-1 et seq.

WHEREAS, Blue Cross & Blue Shield Of Rhode Island, Neighborhood Health Plan Of Rhode Island, and UnitedHealthcare of New England, Inc. provide medical care to the RI Care enrollees through agreements with the RI Department of Human Services, and must comply with performance measures related to lead screening according to the signed contract with the Medicaid agency,

THEREFORE, it is agreed that HEALTH, Blue Cross, Neighborhood, United and DHS will abide by the duties and responsibilities herein described.

This Collaborative Agreement is entered into by and between the Rhode Island Department of Health (hereinafter "HEALTH") Blue Cross & Blue Shield of RI (hereinafter "BCBSRI"), Neighborhood Health Plan of RI (hereinafter "NHPRI"), UnitedHealthcare of New England, Inc. (hereinafter "UHC") and the Rhode Island Department of Human Services (hereinafter "DHS") to engage in a collaborative, mutual exchange of data sets to further the following mutual objectives:

Measure and improve lead screening rates in Rhode Island children under six years of age, in accordance with the measure recommended and approved by DHS and HEALTH.

Share with HEALTH sufficient data provided by each of the health plans twice per calendar year, or as scheduled and agreed by the parties, and use these data to develop and implement joint Quality Assurance/Quality Improvement efforts related to lead screening.

Evaluate current programs and efforts designed to prevent lead poisoning in the state, specifically related to the Medicaid population.

Support policy discussion with respect to current, new and improved lead screening services to children with elevated lead levels, and take appropriate measures to formulate policies.

Make reasonable and joint efforts to prevent children enrolled in the Medical Assistance program from becoming lead poisoned.

### **III. JUSTIFICATION FOR EXCHANGE OF INFORMATION**

Federal requirements under the law: Section 1902 (a) (7) of the Social Security Act (as amended) provides safeguards which restrict the use or disclosure of information concerning Medicaid applicants and recipients to purposes directly connected with the administration of the State plan. Regulations at 42 CFR 431.302 specify the purposes directly related to State plan administration, as including, but not limited to (a) establishing eligibility; (b) determining the amount of Medical Assistance; (c) providing services for recipients; and (d) conducting or assisting an investigation, prosecution, or civil or criminal proceeding related to the administration of the plan.

In the furtherance of the above described purposes, and for the purpose of the general administration of the DHS programs outlined herein, the Rhode Island Department of Human Services supports the exchange and match the particular data described herein with BCBSRI, NHPRI, UHC and the Department of Health to ensure that those eligible and in need of proper Medical Assistance and lead screening will receive it.

The Department of Health, in furtherance of its charge to protect the public health by reducing exposure to lead sources and enhancing lead screening rates, thereby preventing lead poisoning, deems it essential to exchange the information identified in this data Sharing Agreement with BCBSRI, NHP, and UHC. Exchange of this information is permitted pursuant to the Confidentiality of Health Care Act, chapter 5-37.3 including, but not limited to sections 5-37.3-4(5).

It is further agreed among the parties that any exchange of information will be in accordance with all applicable federal and state laws specifically, the state and federal laws applicable include, but may not be limited to, with respect to confidentiality are: Rhode Island General Laws, 5-37.3, 40-6-12, 40-5.1-30, 42-12-4; 42 USC 1396a (a) (7); 42 USC 602(a)(1)(A)(iv); 45 CFR 205.50; 42 CFR 431 part 300-307.

#### **IV. WORKGROUP**

HEALTH, BCBSRI, NHPRI, UHC and DHS agree to participate in an ongoing workgroup to implement, maintain, update, renew and otherwise assure that the present Agreement is adhered to by all parties. The workgroup shall meet at least quarterly, and shall consist of:

(For DHS): the Administrator of the Center for Child and Family Health, or designee(s); and

(For HEALTH): the Administrator of the Childhood Lead Poisoning Prevention Program, or designee(s).

(For BCBSRI): the Rite Care Product Manager, or designee(s).

(For NHPRI): the Health and Wellness Specialist or designee(s).

(For UHC): the Executive Director of the Medicaid Program or designee(s).

All decisions must be made with agreement from each agency's representatives.

Each agency will also secure the presence and/or assistance of suitable technical and/or analytic staff to the Work Group as required. It will be the Work Group's primary responsibility to:

- address specific questions involving this Data Sharing agreement.
- finalize specifications for the transmission of the respective data files.
- facilitate and oversee communications between DATA/MIS/IT staffs of the respective agencies to ensure data completeness, to review the appropriateness of matching algorithms, and to troubleshoot mutual data issues as they arise.

## V. CORE ACTIVITIES

HEALTH, BCBSRI, NHP, and UHC agree to forward to HEALTH data sets subject to change as mutually agreed by the parties, for the purposes above stated. The Health Plans will submit lead screening data from their claims' system to HEALTH using file layouts and specifications determined by HEALTH.

Data elements to be made available for use under this collaborative agreement are summarized below. (The complete initial list of specific data elements corresponding to the summary is attached as Appendix "A".)

Data from BCBSRI, NHPRI and UHC to HEALTH will include:  
standard demographic information of all children known to the Medical Assistance program who are less than or equal to twenty-four (24) months of age, along with data elements necessary to match them to the HEALTH Lead Elimination Surveillance System (LESS).

Once matched, HEALTH will forward to the health plans  
all names and addresses of children participating in the respective health plans, who are tested for blood lead levels above 10 mcg per dl, along with data elements necessary to match them to the health plans data.

HEALTH agrees to utilize the Health Plans data to match with lead screening data existent in the LESS database to identify Health Plans' enrollees screened or in need of lead screened, and report individually identifiable results of the data match to the individual health plan(s). All parties agree that aggregate results of the data match will be made available to all parties, for quality assurance/quality improvement purposes and to use such aggregate results to formulate joint quality efforts and policy development.

Upon mutual agreement, the parties may exchange other datasets than those specified in this section with the understanding that such exchanges would also be subject to all provisions of this agreement, and conditions of such data sharing will be in writing, and specifically delineated in addendum to this agreement.

## VI. USES OF DATA

With regard to the uses of the data resulting from this data exchange, all parties agree to:

- Discuss preliminary results with representatives from all parties;
- Share findings of preliminary matches for feedback, clarification, and reanalysis if needed;
- Hold joint discussions about any formal and semi-formal channels to publish reports, updates, or other products of the collaboration and data analysis and ensure that all parties agree to participate in such publication of data, which shall be published in an aggregate basis only, using only de-identified information as that term is defined under HIPAA.

- Prominently credit the respective partners involved in providing part of the necessary data in all publicly distributed uses of data covered by this agreement, as well as to assure that confidentiality of medical information has been appropriately maintained.

## **VII. METHOD OF DATA ACCESS OR TRANSFER**

A secure means of data transfer consistent with federal and state requirements will be determined by the parties. Specific safeguards will be established to assure the confidentiality and security of individually identifiable records or record information. If encrypted identifiable information is transferred electronically through means such as the Internet, then said transmissions shall be consistent with the rules and standards promulgated by Federal statutory requirements regarding the electronic transmission of identifiable information.

This agreement represents and warrants further that, except as specified in an attachment or as authorized in writing, such data shall not be disclosed, released, revealed, showed, sold, rented, leased, loaned or otherwise have access granted to the data covered by this agreement to any person.

Access to the data covered by this agreement shall be limited to the minimum number of individuals necessary to achieve the purpose stated in this section and to those individuals on a need-to-know basis only. Specifically, Health Plans' data shall not be shared with programs or divisions at HEALTH other than those working as part of the Childhood Lead Poisoning Prevention Program.

## **VIII. DISPOSITION OF DATA**

When this agreement is terminated, any and all the parties involved who still have confidential data as a result of participation in this data exchange agreement, agree to destroy all confidential information associated with actual records and notify all other partners to this effect in writing.

(Note: At the time of signing this document, the Department of Health is the only party that is receiving data from the Health Plans, as a result of this agreement. Upon termination of this agreement, it is agreed that the Department of Health will destroy all hard copies and erase other electronic data that was submitted by the Health Plans for purposes of this agreement.)

If upon termination of this agreement other parties are also in possession of data under similar circumstances as the Department of Health, they agree to also destroy all such data either from hard copies or electronic formats.)

## **IX. CONFIDENTIALITY**

All parties agree to protect the confidentiality of data pertaining to individuals as follows:

The names of individuals, or information that could be linked to an individual, cannot be released or presented in data analysis (including maps) in any manner that could reveal the identity of individuals.

Individual addresses, or results of data analysis (including maps) can not be released in any manner that would reveal individual addresses

Parties shall comply with all Federal and State laws and regulations governing the confidentiality of the information that is subject of this Agreement.

Data transferred pursuant to the terms of this Agreement shall be utilized solely for the purpose set forth in this Agreement.

Releasing or sharing data except as otherwise provided herein shall not be done without written prior approval from the data provider, and then only in accordance with the law.

Any summary results in aggregate form using de-identified information, can be shared if approved by the parties.

HEALTH agrees to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it, in conformity with applicable law and current industry standards.

**X. PERIOD OF AGREEMENT AND TERMINATION**

This agreement shall remain in full force and effect for one year, at which time it will be considered automatically renewed for successive terms of one year, unless it is terminated. This agreement may be terminated by either party if there is a substantial breach of the obligations described herein, or by mutual written agreement of the parties. In either case, there will be at least sixty days (60) advance notice prior to termination of this agreement.

In witness whereof, the Rhode Island Department of Health, the Rhode Island Department of Human Services, Blue Cross and Blue Shield of RI, Neighborhood Health Plan of RI, and United Healthcare of New England, Inc., through their duly authorized representatives, have hereunto executed this Agreement as of the last date below written.

\_\_\_\_\_  
Magaly C. Angeloni  
Program Manager, RI Department of Health  
Childhood Lead Poisoning Prevention

Date\_\_\_\_\_

\_\_\_\_\_  
RI Department of Human Services

Date\_\_\_\_\_

\_\_\_\_\_  
Raymond Brown  
Assistant Vice President, Program Management  
Blue Cross & Blue Shield of RI

Date\_\_\_\_\_

\_\_\_\_\_  
Karen Fifer Ferry  
Chief Financial & External Affairs Officer  
Neighborhood Health Plan of RI

Date\_\_\_\_\_

\_\_\_\_\_  
Patrice Cooper

Executive Director, Medicaid  
UnitedHealthcare of New England, Inc.

Date \_\_\_\_\_

APPENDIX « A »

**Overview:**

The Childhood Lead Poisoning Prevention Program uses this process to read a consistently formatted data file from various sources for the purposes of matching children's information with data in the Lead Elimination Surveillance System (LESS) database.

The process will first use the social security number (SSN) and Date of Birth or, in the case of no matching SSN, it will attempt to utilize the first name, last name and date of birth and the existing matching algorithm provided within the (LESS) application.

Note: This file layout is subject to change upon mutual agreement of the parties, depending on the technical and/or programmatic needs of the parties involved in this agreement.

DATA REQUEST FORM

2 files are requested

File Specifications for LEAD SCREENING Data Match

Page 1 of 3

**DATA REQUEST INFORMATION:**

Requested by:

Department:

Phone:

Date:

Date required by:

**SECTION I.**

**SELECTION CRITERIA:**

Children born in the months of \_\_\_\_\_

Plan's claims data does or does not have a CPT 83655 code, the presence or absence of which is indicated in field 14

**Are RI residents (exclude residents from all other states)**

Must have active enrollment as of \_\_\_\_\_

**FORMAT:**

Once the selection has been made, save it in an electronic file, following specifications below:

**ASCII format,**

**With tab delimited fields, and,**

**A carriage return** separating each child's record.

Each record should contain the fields listed on the table below:

**Table 1. Format of DHS/MCO Data File Used in the Matching Process**

***Note: Tab-Delimited File, First data line of the file should include field names***

| <u>Field Description</u>            | <u>Edit</u>           | <u>Comment</u>   |
|-------------------------------------|-----------------------|--|
| Source_of_Data<br>(ie, UHC, BC,NHP) | Char                  | Codes will be added to SQLTable: and Weights, consistent with other import processes   |
| Gender                              | Char                  | M or F   |
| Birth_Date                          | Integer<br>(YYYYMMDD) |  |
| Race_Code                           | Char                  |  |
| Medicaid_ID_Number                  | Integer               | Equivalent to a Social Security Number   |
| Town_Code                           | Char                  |  |
| Zip-Code                            | Integer               |  |
| Unique_Identifier                   | Integer               | Policy number, unique ID for this member that will match to field 13 on Table 2  |
| First_Name                          | Char                  | DHS can supply only 11 chars, but other sources may supply additional chars up-to maximum of RICLPPP   |
| Last_Name                           | Char                  | DHS can supply only 15 chars, but other sources may supply additional chars up-to maximum of RICLPPP   |
| Middle_Initial                      | Char                  |  |
| Current_Patient_Name_Indicator      | Char                  | Will be valued at a "C" if a record contains the most current version of the patient's name  |
| Date__Modified                      | Integer<br>(YYYYMMDD) | Contains the date of modification to the individual record (AKA update date). Therefore, the most recent date represents the most current information available. |

Table 2

| Field Name                                 | Max. Field Length Allowed by Stellar | Edit Type                           |
|--|--------------------------------------|-------------------------------------|
| Child's Last Name                          | 20 characters                        | Alpha/Numeric                       |
| Child's First Name                         | 15                                   | Alpha/Numeric                       |
| Child's Middle Initial                     | 1                                    | Alpha/Numeric                       |
| Child's Date of Birth                      | 10                                   | MM/DD/YYYY                          |
| Child's Gender                             | 1                                    | M or F                              |
| Street Address (number and street name)    | 20                                   | Alpha/Numeric                       |
| City/Town                                  | 17                                   | Alpha/Numeric                       |
| State                                      | 2                                    | Alpha, standard state abbreviations |
| Zip  | 5                                    | Numeric with leading zeros          |
| Primary Care Provider                      | 30                                   | Alpha/Numeric                       |
| Parent/Guardian's Full Name (First & Last) | 20                                   | Alpha/Numeric                       |
| Name of Health Plan submitting data        | 40                                   | Alpha/Numeric                       |
| Unique Identifier (policy number)          | 40                                   | Alpha/Numeric                       |
| CPT code 83655 Indicator                   | 1                                    | Alpha/Numeric<br>Y=Yes N=No         |
| Rite Care Member                           | 1                                    | Alpha/Numeric<br>Y=Yes N=No         |
| Social Security number                     | 9                                    | Alpha/Numeric                       |

For technical questions regarding the data format, electronic submission and other data questions, you can contact Thony Vongchampa, [Thony.Vongchampa@health.ri.gov](mailto:Thony.Vongchampa@health.ri.gov) or 222-5938.

**APPENDIX 5**

**Parent Reminder Letter for Unscreened Child at 15 Months**

Rhode Island Department of Health  
Childhood Lead Poisoning Prevention Program

August 2, 2005

Dear Parent:

We hope you and your family are doing well! Part of making sure your eighteen-month-old child stays healthy includes having your child tested for Lead Poisoning. According to records kept by the Rhode Island Department of Health's Lead Program, your child has not been tested yet.

The Department of Health recommends that children receive a lead test yearly starting at 9 months. A lead test is a simple blood test that your doctor can order. If your child has already been tested, please disregard this notice. Otherwise, call your doctor to schedule lead testing for your child.

If you would like further information regarding lead poisoning, please contact Judy Garcia, at 222-5374. Thanks for your attention.

Sincerely,

Peter R. Simon, MD, MPH  
Assistant Medical Director  
Division of Family Health

Outreach project

MAKE HE<sup>♥</sup>ALTH PART OF YOUR FAMILY



**APPENDIX 6**

**Lead Screening and Referral Guidelines for Refugee Children**

RHODE ISLAND DEPARTMENT OF HEALTH  
LEAD SCREENING AND REFERRAL GUIDELINES FOR REFUGEES



UNIVERSAL BLOOD LEAD SCREENING REQUIREMENT FOR REFUGEES

Screen all refugee children ages 6 months through 16 years of age (6 months - 191 months) with a venous blood lead test upon entry to the United States at the initial refugee health assessment (recommended within 30 days of arrival and mandated within 90 days of arrival).

The following outlines risks that may be specific to refugee children:

1. Children may have pre-existing health burdens, such as chronic malnutrition, and may have barriers (i.e. language, cultural boundaries) that put them at higher risk for lead poisoning.
2. Children may mouth or eat non-food items, such as soil, which may put them at increased risk for lead poisoning despite the age of the housing in which they are living.

VENOUS BLOOD LEAD SCREENING GUIDELINES FOR REFUGEES

| Venous Blood Lead Level (BLL) | Recommended Actions For Primary Care Provider  | Actions Taken by the Rhode Island Department of Health   |
|-------------------------------|--|--|
| <10 µg/dL                     | <ul style="list-style-type: none"> <li>Repeat blood lead test within 3 to 6 months for children 6 months through 16 years of age.</li> </ul>   | <ul style="list-style-type: none"> <li>Monitor follow-up screening performed within 6 months (180 days).</li> <li>No action taken unless exposure sources change.</li> </ul>   |
| 10-14 µg/dL                   | <ul style="list-style-type: none"> <li>Retest child within 3 months (90 days).</li> <li>Explain child's lead level to parents.</li> <li>Educate family on lead sources and exposures.</li> <li>Test siblings if concern is present.</li> <li>Provide lead education (for brochures, call 1-800-942-7434).</li> </ul> | <ul style="list-style-type: none"> <li>Mail lead educational materials directly to parents. Work with the Refugee Resettlement Agencies to translate and explain the materials as needed.</li> <li>Work with the Refugee Resettlement Agencies to encourage families to accept a Family Outreach Program visit. Families living in Providence are also offered a home inspection.</li> <li>Monitor follow-up screening performed within 3 months (90 days).</li> </ul> |
| 15-19 µg/dL                   | <ul style="list-style-type: none"> <li>Follow same recommendations for venous BLL 10-14 µg/dL.</li> <li>Inform family that they have been referred by the Department of Health for non-medical case management services provided by a lead center.</li> </ul>  | <ul style="list-style-type: none"> <li>Refer family to a lead center for non-medical case management services (free lead education home visit, visual assessment, risk assessment, and follow-up screening).</li> <li>Work with Refugee Resettlement Agencies to encourage acceptance of services from a lead center.</li> <li>Track all referrals for case management.</li> <li>Monitor follow-up screening performed within 3 months (90 days).</li> </ul>           |
| 20-44 µg/dL                   | <p>Child needs medical evaluation and treatment. You can refer for medical follow-up at:</p> <ul style="list-style-type: none"> <li>Hasbro Lead Clinic: 444-5255</li> <li>St. Joseph's Lead Clinic: 456-4310</li> <li>Memorial Hospital: 720-2831</li> </ul>   | <ul style="list-style-type: none"> <li>Refer family to a lead center for non-medical case management services (free lead education home visit, visual assessment, risk assessment, and follow-up screening).</li> <li>Work with Refugee Resettlement Agencies to encourage acceptance of services from a lead center.</li> <li>Track all referrals for case management.</li> <li>Refer for an environmental inspection if child is under 6 years of age.</li> </ul>    |
| ≥ 45 µg/dL                    | <ul style="list-style-type: none"> <li>If venous BLL screening is ≥ 45 µg/dL, repeat test immediately as a stat lab test. If stat lab test result is ≥ 45 µg/dL, consider hospitalization.</li> <li>Follow same recommendations for venous BLL 20-44 µg/dL.</li> </ul>   | <ul style="list-style-type: none"> <li>Expedite a referral for non-medical case management services provided by a lead center.</li> <li>Refer for an environmental inspection if child is under six years of age.</li> </ul>   |

**Questions?**  
Call Patricia Raymond, RN, at the Rhode Island Department of Health, (401) 222-5921

**Online Information**  
Childhood Lead Poisoning Prevention Program,  
[www.health.ri.gov/lead](http://www.health.ri.gov/lead)

**Rhode Island Department of Health**

|                                     |              |
|-------------------------------------|--------------|
| Family Health Information Line..... | 800-942-7434 |
| Refugee Health Program.....         | 222-2001     |
| Division of Family Health.....      | 222-2312     |
| Environmental Health.....           | 222-1417     |
| Laboratory.....                     | 222-5600     |

**Refugee Resettlement Agencies**

|  |               |
|--|---------------|
| International Institute of Rhode Island..... | 461-5040      |
| Diocese of Providence.....                   | 421-7833 x131 |

**Lead Centers**

|   |               |
|---|---------------|
| Blackstone Valley Community Action..... | 723-4520 x227 |
| HELP Lead Safe Center.....              | 421-8595      |
| Westbay Community Action.....           | 732-4660      |

**Additional Resources**

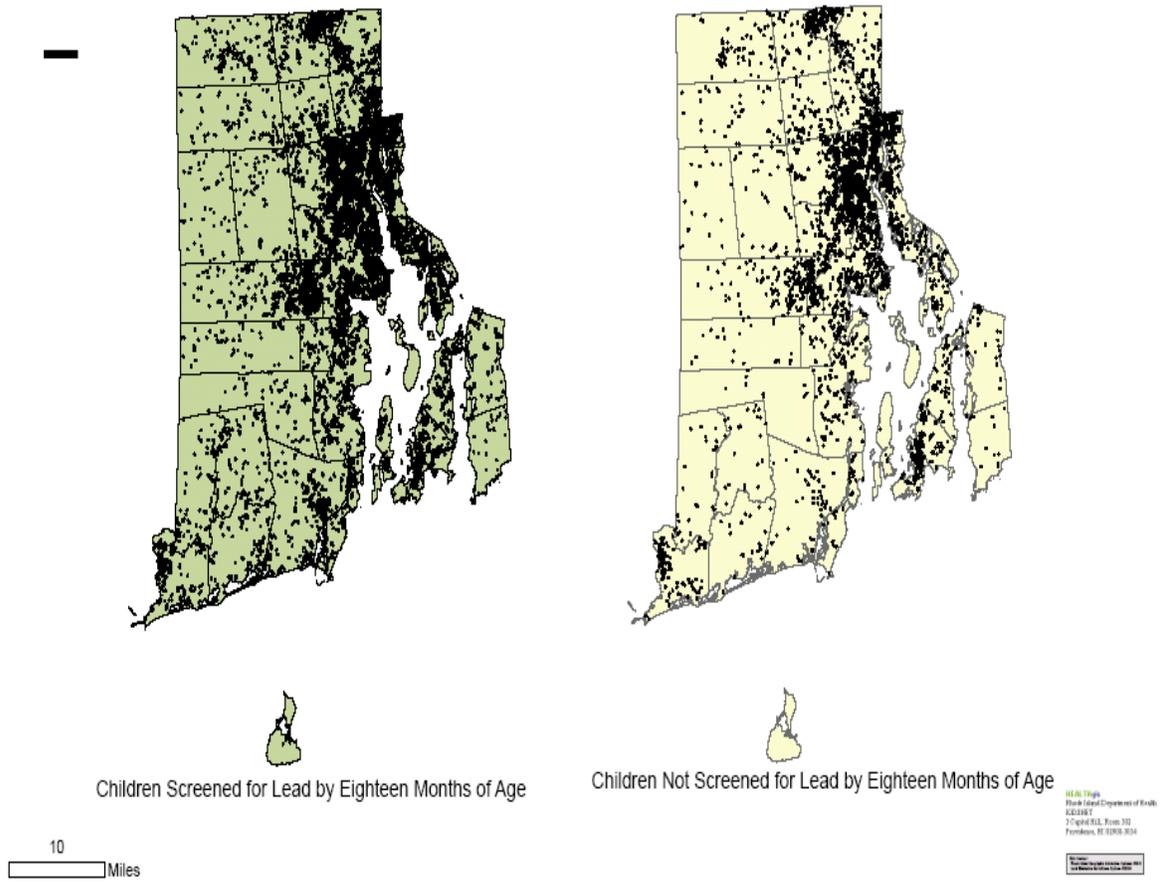
|   |          |
|---|----------|
| Rhode Island Housing.....                   | 751-5566 |
| Department of Environmental Management..... | 222-1360 |
| Childhood Lead Action Project.....          | 785-1310 |

**APPENDIX 7**

**Distribution of Rhode Island Children Screened Once by 18  
Months of Age**

Distribution of Rhode Island Children Screened Once by 18 Months of age

Lead Screening Status of Children Born Between 01/01/2000 and 12/31/2001



**APPENDIX 8**

**Policy for Lead Screening Specimen Analysis**

## POLICY FOR LEAD SCREENING SPECIMEN ANALYSIS

### Background: Lead Law and Regulations.

The "Lead Poisoning Prevention Act" of the RI General Law, Chapter 23-24.6-7, numeral (5) states that "all blood lead samples taken by physicians or other health care providers licensed in Rhode Island or by licensed, registered, or approved health care facilities in Rhode Island from children under the age of six (6) years for the purpose of screening for blood lead level *shall be sent to the state laboratory* in the department of health for laboratory analysis."

According to the Rules and Regulations for Lead Poisoning Prevention, as amended on February 1992, section 3.2 "Childhood Blood Lead Screening," literal (a), related to the Screening Samples, "all blood lead screening test samples, including venipuncture screening samples and capillary blood lead samples taken from children under six years of age at the request of a physician or other health care provider licensed in Rhode Island, or as part of a child health program partially or fully funded by State funds or administered by any State agency, shall be submitted to the Department laboratory for analysis, unless the Department has approved use of another laboratory."

**Goals.** The Department of Health is highly committed to the performance of public health functions of assessment, assurance and policy development, and the elimination of childhood lead poisoning. Within the public health goals, the Department of Health must conduct surveillance of the blood lead levels in children under six residing in the state, and must meet the mandate to collect all the lead screening data.

**Conditions.** In order to perform its surveillance function without unduly impacting clinical services for lead poisoned children, the Department has approved the analysis of blood lead screening specimens to be conducted in two facilities, in addition to the State Laboratory: Saint Joseph's Hospital and Rhode Island Hospital. These facilities agree to meet the following conditions:

**Surveillance.** To increase and/or enhance lead screening, reporting and surveillance in Rhode Island children under the age of six,

**Case Identification.** To allow timely identification of cases with elevated blood lead levels, and coordinate with inpatient and outpatient management of lead levels greater than or equal to 45 mcg/dL,

**Certification.** To meet the requirements of state licensure by the Department of Health R23-16.2C&S/LAB and federal certification as set forth in the Clinical Laboratory Improvement Amendments of 1998 (CLIA).

**Equipment/methods.** The equipment and methodology used by the laboratory meets minimum standards to ensure that accurate results are provided. Anodic Stripping Voltammetry (ASV) or Graphite Furnace Atomic Absorption Spectroscopy (AAS) are acceptable laboratory methods. The use of other laboratory methods for the analysis of blood lead screening specimens requires prior approval by the Department.

**Proficiency testing.** Successful performance in an approved proficiency testing program must be maintained by the laboratories.

**Location.** The laboratories serve and function in conjunction with a Department of Health's approved Lead Clinic, meeting CDC, AAP guidelines and JCAHO (for the medical treatment of

lead poisoned children) or a large pediatric practice or practices located within ONE physical location, and for which, in order to efficiently serve the patient population and to facilitate providers' routing of lead screening orders the on-site analysis.

Renewal. A Memorandum of Understanding is signed and reviewed every two years or more often if needed.

Reporting. The laboratories agree to report lead screening results weekly, in electronic format previously approved by the Department.

Other conditions.

- a. The laboratory may not subcontract the analysis of blood lead specimens with other laboratory in or outside of the state of Rhode Island, unless specifically approved by the Department of Health.
- b. If it is decided that due to financial, technical, mechanical, operational, resources, quality of testing or other issues, the laboratory can not adequately function for a period of two weeks or more, the Chief of Environmental Sciences from the State Laboratory must be contacted at 222-5600 and be timely notified. Upon notification, efforts will be made to conduct blood lead specimens analysis at the State Laboratory until such time when the authorized laboratory is able to resume their ongoing regular functions.
- c. An annual meeting would be held, if necessary, at the time of agreement renewal. The meeting would be held for purposes of reviewing terms of the agreement, reporting issues, operational or other technical or management issues.
- d. The approved laboratories will be notified in writing, in the cases of regulatory changes that may affect any or all the terms of the agreement.

The Rhode Island Department of Health reserves the right to adjust and/or modify the conditions of this policy to comply with newly required regulations, to further improve lead screening status for the RI population or as decided by the Director of Health.

This policy was drafted and implemented by the Rhode Island Childhood Lead Poisoning Prevention Program in 2004.

**APPENDIX 9**

**Lead Center Memorandum of Understanding**

**MEMORANDUM OF UNDERSTANDING BETWEEN  
THE RHODE ISLAND DEPARTMENT OF HEALTH AND LEAD CENTER**

This Memorandum of Understanding is entered into as of the 27th day of April, 2005, by and between the Rhode Island Department of Health (hereinafter "HEALTH") and Lead Center (hereinafter "Lead Center") for the purpose of providing children identified by HEALTH as significantly lead poisoned children (or populations as jointly agreed among the Rhode Island Department of Human Services (DHS), HEALTH, and the Lead Center) with access to coordinated comprehensive care.

WHEREAS the mission of HEALTH's Childhood Lead Poisoning Prevention Program is to "prevent childhood lead exposure and poisoning," by ensuring children are lead screened and offered follow-up services, including case management, environmental assessment, and medical treatment,

WHEREAS the Lead Center established operations in January 2003, for purposes of providing comprehensive care to significantly lead poisoned children in Rhode Island,

WHEREAS the Lead Center is funded and certified by DHS (the state's Medicaid agency) as a provider of medical care coordination, non-medical case management, lead education and training, and housing relocation assistance to lead poisoned children as established in the Lead Center Specifications issued by DHS,

WHEREAS KIDSNET is an operational information system within HEALTH that contains select information from nine different Maternal and Child Health (hereinafter "MCH") programs. KIDSNET contains child and address/environment-specific information, creating a child profile for each child born in Rhode Island (as well as those who have moved into state and access or receive one of the nine MCH program services),

WHEREAS the KIDSNET system includes lead screening information pertaining to children born on or after January 1, 1997, and the Lead Center is responsible for providing case management services, including coordination of medical care.

Based upon the foregoing, it is agreed that HEALTH shall refer cases of significantly lead poisoned children (or refer populations as jointly agreed among DHS, HEALTH, and the Lead Center) to the Lead Center, and that the Lead Center shall have permission to access information as specified below through KIDSNET, and that both parties will abide by the terms and conditions of this Memorandum of Understanding.

**Duties and Responsibilities**

With regard to the Lead Program, HEALTH shall fulfill the following duties as part of this Agreement:

1. Refer to the Lead Center the population of lead-poisoned children as jointly agreed among DHS, HEALTH and the Lead Center.

2. Prepare forms and information necessary to refer children to the Lead Center at least on a weekly basis or more often as needed and as commonly agreed, via fax, modem, or mail, as technology allows.
3. Include the Lead Center on multidisciplinary teams to develop, update, and revise HEALTH's case management policies, protocols and/or procedures for significantly lead poisoned children (or populations as jointly agreed among the DHS, HEALTH, and the Lead Center).
4. Formulate a joint Quality Assurance plan in collaboration with DHS and the Lead Center to improve the quality of case management services for lead-poisoned children, and facilitate/assist with the formulation or provision of information necessary to implement the Quality Assurance plan.
5. Evaluate case management activities in the state to ensure compliance with any federal (CDC), state or other recommendations or studies pertaining to case management services to lead poisoned children. Evaluation efforts will involve all agencies/parties providing services, including, but not limited to, discussing evaluation framework; developing outcome measures; conducting chart reviews on site; conducting parent focus groups, parent satisfaction surveys and/or other kinds of assessments; presenting preliminary and final findings and recommendations to the multidisciplinary team of parties involved, including the Lead Center, and jointly developing and implementing action plans to address findings identified in the evaluation of the case management's system in the state
6. Offer the Lead Center the opportunity to participate in other outreach and education efforts, such as Rhode Island's "Lead Poisoning Prevention Month" in May, national "Lead Poisoning Prevention Week" in October, and others as needed and resources allow.
7. Provide duct tape and cleaning supplies (TSP) to the Lead Center for distribution to families of lead poisoned children. These supplies will be provided on a yearly basis or more often as needed and/or as resources and state procurement requirements allow.
8. Work with DHS and the Lead Center to design, revise, formulate and implement protocols for the provision of case management services in the state, including, but not limited to the protocol for processing referrals of Urgent Levels of Lead Poisoning ( $Pb \geq 45\mu\text{g/dL}$ ), contacting families, educating families about lead poisoning and others.
9. Participate with the Lead Center in the visual assessment of the primary residence of severely lead poisoned/hospitalized children. HEALTH will document environmental findings on a form provided by the Lead Center. This form will assist the case management team in determining if discharge to the home is appropriate.
10. Perform a visual assessment with the Lead Center if alternative housing is necessary for hospital discharge, utilizing the same protocol as in the case of a primary residence.
11. Conduct site consults with owners to review specific lead hazards identified in the Comprehensive Environmental Lead Inspection, discuss the scope of work required, review appropriate methods for abating lead hazards, and monitor the progress of lead hazard remediation.
12. Re-evaluate a property, as needed, and upon completion of the environmental inspection, to determine if it qualifies for the spot repair exemption from the requirement to utilize a licensed lead hazard reduction contractor.

13. Conduct clearance inspections when lead hazard remediation is completed and issue a certification of lead safe status as appropriate.
14. Provide environmental case status updates to the Lead Center as requested.

With regard to the KIDSNET Program, HEALTH shall fulfill the following duties as part of this Agreement:

15. Provide the Lead Center access to the following KIDSNET screens: Search, Demographics, Home Visiting, Lead, WIC and Early Intervention, in order to facilitate the Lead Center's coordination of case management services with other providers, upon signing the KIDSNET User Agreement
16. Train and support Lead Center staff in the appropriate use of the KIDSNET system, including all confidentiality requirements.
17. Ensure that KIDSNET's system updates and upgrades are available to the Lead Center.
18. Be available for executive or technical meetings about the possible expansion of the Lead Center's access to the KIDSNET system.
19. Receive new demographic information reported by the Lead Center regarding specific children in the KIDSNET system.
20. Facilitate contacts with the KIDSNET participating programs at the state level for policy clarification, coordination of services, quality assurance or other efforts as mutually agreed upon or as required by federal and other mandates.
21. Develop and implement, within a reasonable timeframe, the appropriate parent consent process in the respective WIC and EI programs, to ensure that parents of children enrolled in WIC/EI are aware and agree to provide access to their information through KIDSNET.
22. Develop and implement, within a reasonable timeframe, a process in the KIDSNET database to block the information pertaining to those WIC/EI recipients whose consent was not granted.
23. Communicate promptly to advice of major policy changes, federal mandates, or other significant structural programmatic changes in the KIDSNET participating programs that may have an impact on Lead Centers. Similarly, to arrange discussion forums or meetings with Lead Centers for purposes of developing action plans to implement such new mandates, as and if needed.

With regard to the Lead Program, the Lead Center shall fulfill the following duties as part of this Agreement:

1. Maintain DHS certification as a Comprehensive Lead Center.
2. Submit written notification to HEALTH when and if the mission, address, location, contact, management structure, leadership and/or other responsibilities of the Lead Center change in such a way as to affect the terms of this agreement.
3. Receive and follow up on all referrals of significantly lead poisoned children (or populations as jointly agreed among DHS, HEALTH, and the Lead Center) sent by HEALTH to the Lead Center.
4. Provide services in accordance with the current DHS Specifications for Comprehensive Lead Centers.
5. Upon referral from HEALTH, take all reasonable measures to contact families within 96 hours, in order to offer Lead Center services. In cases in which the blood lead level is equal to or exceeds 45 µg/dL, attempt to contact and engage in discharge planning with

- the family within 4 hours of being formally notified of a referral or a hospital admission. Follow all related guidelines outlined in HEALTH's Protocol for Processing Referrals of Urgent Levels of Lead Poisoning (Pb  $\geq$  45 $\mu$ g/dL).
6. Participate in the development, update, revision and implementation of HEALTH's case management policies, protocols and/or procedures for significantly lead poisoned children (or populations as jointly agreed among DHS, HEALTH, and the Lead Center).
  7. Take all reasonable measures to inform property owners and inform clients regarding HEALTH's programs and the expected process to achieve a lead safe dwelling.
  8. Take all reasonable measures to facilitate initial contact between property owners and HEALTH's Environmental Lead Program.
  9. Educate clients in environmental interim controls to minimize lead exposure and monitor implementation of said interim controls.
  10. Maintain current information on the sources of funding for lead hazard reduction work and refer property owners to such sources to ensure lead hazard reduction in the property.
  11. Assess the family's eligibility for spot repairs in the house of RiteCare eligible children receiving services from the Lead Center, and make arrangements needed to ensure the spot repairs are made in the unit, if eligible.
  12. Notify HEALTH within a reasonable timeframe about any issues (including data errors) or changed circumstances that bear significantly on HEALTH's responsibilities.
  13. Request HEALTH's input in the development of strategic plans, evaluations, policies, and protocols relating to the Lead Center's case management of significantly lead poisoned children (or populations as jointly agreed among DHS, HEALTH, and the Lead Center) and other joint ventures of HEALTH and the Lead Center (e.g., education and outreach).
  14. Formulate a joint Quality Assurance plan in collaboration with DHS and HEALTH to improve the quality of case management services for lead-poisoned children and provide the information necessary to implement such plan.
  15. Support HEALTH'S responsibility to ensure the provision of quality care to lead poisoned children. For purposes of verification of data, further collection of information, auditing and quality assurance, HEALTH will have physical access to records annually or as otherwise agreed by the two parties.
  16. Participate and provide input, support and facilitate data collection for HEALTH's evaluation efforts to measure the impact of case management activities in the state.
  17. Meet with HEALTH's officials to discuss planning and evaluation issues and revise this Memorandum of Understanding, as needed. Meetings will be scheduled on a quarterly basis or as otherwise agreed by the two parties.
  18. Submit monthly activity reports and data to HEALTH in electronic and/or hard copy formats and work with HEALTH on issues related to electronic data submission, as technology allows and as agreed by the two parties to ensure systems' compatibility. Reporting includes, but is not limited to:  
Cases Refused During the Month Closed Case Reports, for all cases closed during the month, with the number and type of services provided and other requested demographic information Other reports, as mutually agreed upon.
  19. Participate in policy discussions or meetings arranged by the Department of Health for purposes of jointly developing action plans when new federal or significant mandates are put in place.

With regard to the KIDSNET Program, the Lead Center shall fulfill the following duties as part of this Agreement:

20. Abide by the KIDSNET policy and confidentiality agreement and all other pertinent federal or state laws or regulations pertaining to confidentiality of clients' information. Ensure that all Lead Center staff accessing KIDSNET have reviewed the KIDSNET policy manual, have been trained in KIDSNET confidentiality policies and procedures, have signed KIDSNET confidentiality agreements, and have such agreements updated annually.
21. Limit access to the KIDSNET system to Lead Center staff on a need-to-know basis, for the sole purpose of facilitating the Lead Center's coordination of case management services with other providers.
22. Report any KIDSNET system failures or missing/invalid information found in the KIDSNET system (e.g., different spellings of a name, new addresses, changes in demographics in the system, change of parents' names, adoption status, etc.) to HEALTH.
23. Request, if desired, written authorization from HEALTH for expanded access to the KIDSNET system (for example, Immunizations, etc.). Any request will be in writing and will detail the nature and purpose of the request, as well as the potential benefits for a specific population.
24. Use the information contained in KIDSNET for purposes of coordinating case management provided by the lead centers' case managers.
25. Communicate promptly with the Department of Health to notify any problems, suggestions or issues that arise regarding the use of KIDSNET.

## Terms and Conditions

**Period of performance.** This Agreement will be effective for a period of one year from the date of execution and will be considered automatically renewed for another year, unless otherwise mutually agreed by the parties, while the Lead Center is certified by DHS as a Comprehensive Lead Center.

**Modification of Agreement.** This Agreement may be amended and/or extended at any time, by mutual written consent of the parties, to more accurately reflect changes in policies, methods, timeframes or other reasonable circumstances, provided that such consent may not be unreasonably withheld.

**Termination of Agreement.** This Agreement may be terminated upon thirty (30) days written notice by mutual agreement of the parties. The above mentioned thirty (30) day written notice notwithstanding, in the event that either party breaches one or more of the terms and provision herein, the affected party reserves the right to require that corrective action be conducted within ten (10) calendar days from the date of the request. If within the ten (10) calendar days no corrective action is taken, the agreement may be deemed terminated immediately.

**Drug Free Workplace policy.** The Lead Center agrees to comply with the requirements of the Governor's Executive Order No. 91-14, the state's Drug Free Workplace Policy, and the federal Omnibus Drug Abuse Act of 1988. The Lead Center acknowledges that a violation of the drug free workplace policy may, at HEALTH's option, result in termination of this Agreement.

**Subcontracts.** In the case that the Lead Center intends to subcontract part or all of its responsibilities outlined in the DHS Specifications for Comprehensive Lead Centers, the Lead Center will promptly notify HEALTH in writing about its intentions to subcontract and provide the subcontractor information (organization/individual's name, contact name, duties covered under the subcontract) before the subcontractor initiates work for the Lead Center. HEALTH will make reasonable efforts to review the subcontract in a timeframe that will not negatively impact the continuation of Lead Center's obligations. HEALTH will communicate the result of the review to the Lead Center in writing, and will also decide if a written agreement with the subcontractor is needed. In the event that a written Agreement is needed, HEALTH will then proceed to work with the subcontractor and the Lead Center on the content of the Agreement. The written Agreement shall be completed no later than sixty (60) days from the date the subcontractor started providing services under its subcontract with the Lead Center. The Lead Center's failure to comply with the provisions of this article could result in breach of the Agreement and be grounds for termination.

**Confidentiality.** The Lead Center agrees to abide by all federal and state laws and regulations governing the confidentiality of information to which it may have access pursuant to the terms of this Agreement. In addition, the Lead Center agrees to comply with the HEALTH confidentiality policy recognizing a person's basic right to privacy and confidentiality of personal information ("Confidential records" are the records as defined in section 38-2-3-(d) (1)-(1-19) of the General Laws, entitled "Access to Public Records" and described in "Access to Department of Health Records"). Failure to abide by HEALTH's confidentiality policy will result in termination of the Agreement and is subject to penalties as stated in the law.

The parties hereto have executed this agreement as of the Effective Date of April 27, 2005.

For Rhode Island Department of Health

For Lead Center

\_\_\_\_\_  
Name

\_\_\_\_\_  
Name

\_\_\_\_\_  
Title

\_\_\_\_\_  
Title

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

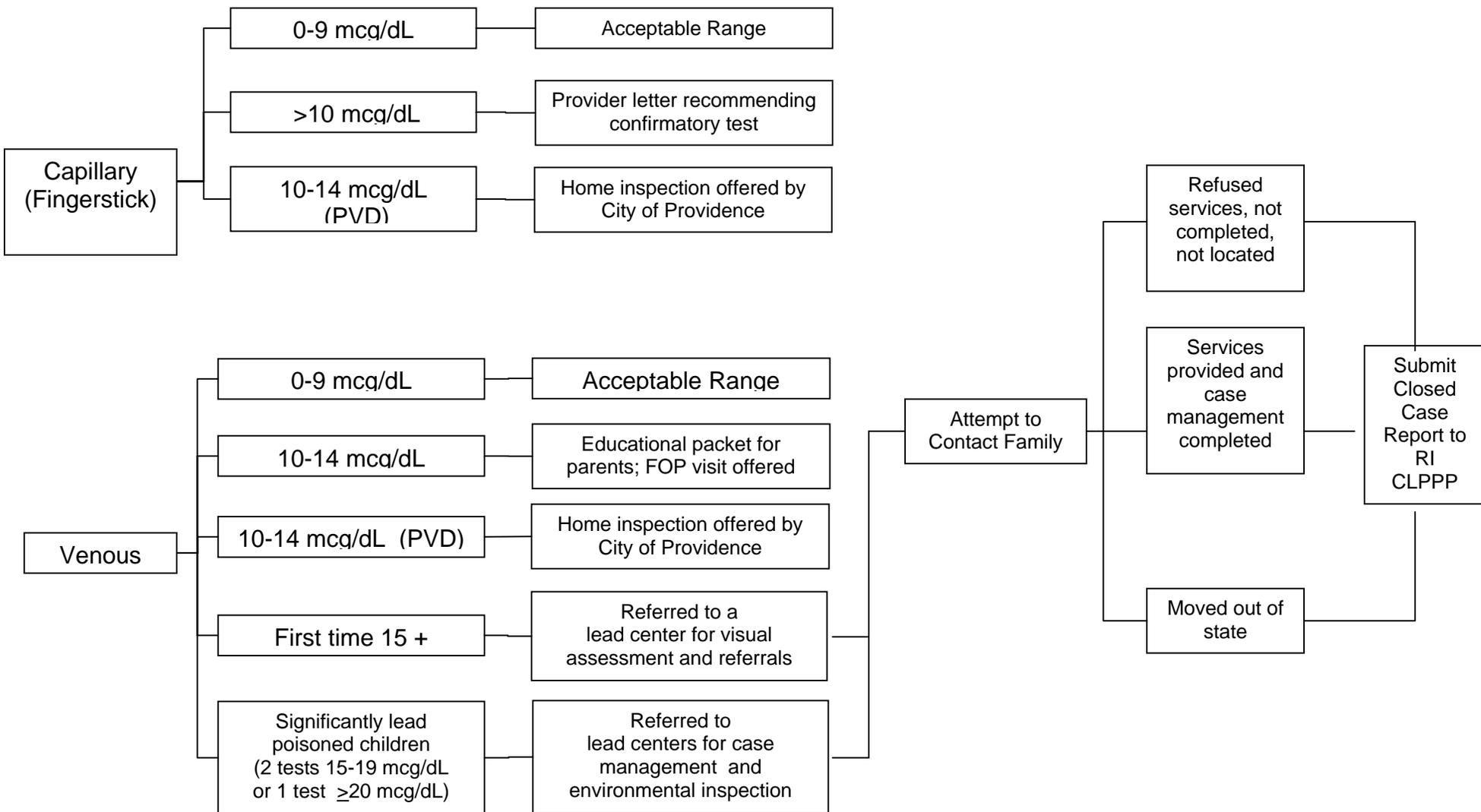
Attachments:

1. RI General Law of Confidentiality of Health Care Information Act, section 5-37.3-4.
2. KIDSNET policy handbook
3. HEALTH's Case Management Protocol
4. Governor's Executive Order No. 91-14 on Substance Abuse Policy
5. Federal Omnibus Drug Abuse Act of 1988
6. Section 38-2-3-(d) (1)-(1-19) of Rhode Island General Laws

**APPENDIX 10**

**Intervention Offered by Blood Lead Level- Flow Chart**

## INTERVENTIONS OFFERED BY BLOOD LEAD LEVEL



RI CLPPP 1/1/2006

**APPENDIX 11**

**Case Management Evaluation**

# Evaluation of Case Management for Lead Poisoning in Rhode Island

Rhode Island Childhood Lead  
Poisoning Prevention Program

January 2003



## Table of Contents

|   |            |
|---|------------|
| <b>STATEMENT OF AUTHORSHIP AND ACKNOWLEDGEMENTS.....</b>          | <b>92</b>  |
| <b>EXECUTIVE SUMMARY .....</b>                                    | <b>93</b>  |
| <b>BACKGROUND.....</b>  | <b>94</b>  |
| <b>METHODOLOGY.....</b>   | <b>96</b>  |
| <b>PARENTAL SURVEY.....</b>                                       | <b>96</b>  |
| <b>DATA ANALYSIS.....</b>   | <b>97</b>  |
| <b>EVALUATION OF CASE MANAGEMENT PROCESS.....</b>                 | <b>99</b>  |
| CAPTURING CASES.....  | 99         |
| NUMBER LOCATED AND NUMBER ACCEPTED OR REFUSED SERVICES.....       | 99         |
| REASONS FOR REFUSING & INTEREST IN ALTERNATIVE SERVICES.....      | 100        |
| DELIVERING SERVICES .....   | 101        |
| TIME TAKEN TO SCHEDULE/RECEIVE INITIAL HOME VISIT.....            | 101        |
| CONVENIENCE OF APPOINTMENT TIMES .....                            | 102        |
| APPROPRIATE LANGUAGE .....  | 102        |
| RELATIONSHIP BETWEEN CLIENT AND CASE MANAGER .....                | 102        |
| ABILITY TO/EASE OF CONTACTING THE CASE MANAGER .....              | 103        |
| CASE MANAGERS COURTEOUS AND RESPECTFUL.....                       | 103        |
| PERCEIVED UTILITY OF CASE MANAGERS.....                           | 103        |
| CASE CLOSURE .....  | 105        |
| ORIGIN AND REASON FOR CASE CLOSURE .....                          | 105        |
| COMFORT LEVEL WITH NUMBER OF VISITS MADE.....                     | 107        |
| <b>EVALUATION OF CASE MANAGEMENT IMPACT .....</b>                 | <b>108</b> |
| RECEIPT OF APPROPRIATE FOLLOW-UP CARE .....                       | 108        |
| PARENT'S AWARENESS OF NEED FOR FOLLOW-UP TESTS .....              | 108        |
| PARENTAL PERCEPTION OF EASE OF HAVING CHILD TESTED FOR LEAD.....  | 109        |
| PERCENTAGE OF CHILDREN RECEIVING FOLLOW UP BLOOD TESTS .....      | 109        |
| REFERRALS TO OTHER AGENCIES INCLUDING WIC.....                    | 111        |
| SIBLINGS OF POISONED CHILDREN SCREENED .....                      | 112        |
| PARENTS RETAIN INCREASED AWARENESS OF LEAD POISONING ISSUES ..... | 112        |
| PARENTS FEEL EFFICACY .....                                       | 112        |
| CASE MANAGER DISCUSSED WHAT PARENTS CAN DO/THEY DID IT .....      | 113        |
| COORDINATION WITH ENVIRONMENTAL INSPECTION .....                  | 114        |
| CASE MANAGER HELPED TO SCHEDULE THE INSPECTION .....              | 115        |
| ACCEPTANCE AND REFUSAL OF INSPECTION.....                         | 115        |
| CASE MANAGER ASSISTED IN INTERPRETING RESULTS OF INSPECTION.....  | 116        |
| INSPECTION PERFORMED AT CONVENIENT TIMES.....                     | 116        |
| LENGTH OF TIME TO RECEIVE INSPECTION RESULT .....                 | 116        |
| RELATIONSHIP WITH LANDLORD.....                                   | 116        |

|  |            |
|--|------------|
| MEASURING DECLINE IN BLOOD LEAD LEVELS .....                           | 116        |
| DECLINE IN BLOOD LEAD LEVEL .....                                      | 117        |
| FAMILY MOBILITY FOLLOWING POISONING .....                              | 119        |
| APPLICATION OF LEAD KNOWLEDGE TO FUTURE HOUSING CHOICES .....          | 119        |
| DIRECT ASSISTANCE FROM CASE MANAGER IN LOCATING SAFER HOUSING.....     | 120        |
| CHILD AND ENVIRONMENT STATUS AT CASE CLOSURE .....                     | 120        |
| CASES CLOSED FOLLOWING COMPLETION OF ENVIRONMENTAL ENFORCEMENT .....   | 120        |
| CASES CLOSED FOLLOWING DECLINE IN BLL TO LESS THAN 20, 15, OR 10 ..... | 120        |
| CASES REMAINING OPEN FOLLOWING DECLINE .....                           | 121        |
| DURATION OF CASES.....   | 122        |
| <b>CONCLUSIONS AND RECOMMENDATIONS.....</b>                            | <b>122</b> |
| CONCLUSIONS .....  | 122        |
| RECOMMENDATIONS.....   | 124        |
| <b>REFERENCES.....</b>   | <b>127</b> |
| <b>APPENDIX I – ENGLISH VERSION OF PARENTAL SURVEY .....</b>           | <b>128</b> |
| <b>APPENDIX II – SPANISH VERSION OF PARENTAL SURVEY .....</b>          | <b>136</b> |

## Statement of Authorship and Acknowledgements

This evaluation was the result of efforts from many individuals within the Rhode Island Childhood Lead Poisoning Prevention Program (RICLPPP). The primary study design, analysis, and writing were done by Patrick MacRoy, Public Health Epidemiologist. Ana Reynoso, Parent Consultant, conducted the parental survey. Ana Novais, formerly the Outreach and Education coordinator, was key in designing and conducting focus groups for testing the survey. Anne Primeau-Faubert, Data Manager, provided numerous datasets, often multiple times, and helped to explain the data systems. Al Cabral, formerly Supervising Industrial Hygienist of the Environmental Lead Program was essential in interpreting the inspection data. Christopher Mooney, a graduate student intern from the Brown University Center for Environmental Studies, helped in the interpretation of the survey data. Special thanks to Magaly Angeloni, Program Manager, for her guidance and support throughout the project.

Additionally, the Lead Management Team and Lead Program Staff of the Department of Health provided advice throughout the project and were key in thinking through the design of the study. In addition to the members previously named, this includes: Rosemary Aglione, Bryan Barrette, Becky Bessette, Walter Combs, Jodie Garnetto, Concetta Goncalves, Bill Hollinshead, Ken Jones, Pat Raymond, Peter Simon, Marie Stoeckel, James Sullivan, Bob Vanderslice, and Amy Zimmerman-Levitan.

While the views expressed in this evaluation, its ultimate design, and any errors are the responsibility of the RICLPPP, the evaluation could not have been conducted without the assistance of our governmental and non-profit partners in Case Management. Nolan Byrne-Simpson and Sharon Kernan provided helpful input on the design and interpretation from the Department of Human Services. Jeremy Giller and June Tourangeau from the HELP Lead Safe Center, and Kristine Campagna and Beth Graziano from Care New England Home Health Care provided input into the design and interpretation of the results. Liana Cassar, formerly of the HELP Lead Safe Center provided input into the design of the study. Pat McLaine, of the National Center for Healthy Housing, and Mary Jean Brown of the Harvard School of Public Health, provided valuable resources, guidance, and an overview of case management for lead poisoning on a national level.

## Executive Summary

This evaluation of case management services for lead poisoning was undertaken to provide an assessment of what the current process and outcomes are for children who become significantly lead poisoned and their families. While it draws comparisons between different service providers and between populations of children who did and did not receive services, it is not designed to, nor is it valid to use the results of this study to infer the relative success of one agency over another or the relative benefits of case management. It does, however, provide a detailed analysis of what children enrolled in case management between 1999 and 2001 experienced and affords the opportunity both for congratulating successes and identifying some areas in need of improvement.

Data for the evaluation was derived from both administrative records kept by HEALTH and from a detailed telephone survey of parents of lead poisoned children. Blood lead levels, case referral records, case reports, and environmental inspection records of the 726 children referred for case management were used to generate quantitative assessments of case management. The 30 to 40 question telephone survey reached 91 parents in English or Spanish to ask about their experiences and to gain a qualitative insight into the success of case management. Parents of children who both accepted and refused services were included in the study.

The evaluation shows that, by and large, the process of case management is running smoothly. Families overwhelmingly found their experience in case management to be helpful, and were so full of praise for their case managers that few could even identify an area for improvement. The case management agencies and their staff are clearly doing an exceptional job at gaining the trust and respect of their clients, and making themselves available in ways and at times convenient for the families. The results also showed that with minimal exceptions, parents completing case management have a solid understanding of lead poisoning and are aware of appropriate strategies for controlling lead hazards.

The evaluation also resulted in several recommendations for improving the case management system in Rhode Island. With 18% of families referred for services either refusing services or not being located, strategies for improving the case capture rate are clearly needed. Similarly, a large number of parents who accepted case management were found to refuse the environmental inspection, limiting the opportunities to address the root cause of the poisoning. The evaluation also highlighted the lack of uniform and measurable standards for determining when a case should be discharged from case management, documenting a wide range of outcomes present in children who completed services. While children in case management had a relatively high compliance rate with receiving follow-up lead tests, increased coordination with PCPs is needed to improve timeliness of follow-up testing. Parents were also found to have an over-reliance in the meaning of "lead-safe" and would benefit from additional education in the importance of long-term vigilance and continued control of lead hazards. Finally, the evaluation recommends better tracking of utilization of referrals to other agencies and further study of the declines in blood lead levels resulting from case management.

## Background

Lead poisoning is amongst the most significant challenges in pediatric health in Rhode Island. Largely a result of the concentration of families with young children in older, wood-frame housing stock, Rhode Island has a statewide prevalence rate for lead poisoning double that of the national average, with some cities having a rate nearly quadruple the national rate. Associated with decreased intelligence, learning difficulties, and behavioral changes, lead poisoning can have life-long impacts for those afflicted. Particularly troubling is that lead poisoning is completely preventable as it is primarily caused by exposure to leaded dust from deteriorating lead-based paint.

To help address this problem, the Rhode Island Department of Health (HEALTH) has established a comprehensive Childhood Lead Poisoning Prevention Program. As required by law, all children in the state, starting at age 9 months and lasting to age six, must be screened at least annually by their doctor for lead poisoning. This is accomplished by measuring the micrograms of lead per deciliter of whole blood (abbreviated  $\mu\text{g}/\text{dL}$ ) in the child. These Blood Lead Levels (BLLs) are reported, as required by regulation, to HEALTH for inclusion in a comprehensive database and for ensuring that poisoned children receive needed services.

The federal Centers for Disease Control and Prevention (CDC) has established a BLL of  $10\mu\text{g}/\text{dL}$  as the level of concern, although this level was not based upon “no adverse effect” standards, and many believe lower lead levels to be harmful. However, beyond family education and continued blood lead level testing, the CDC does not generally recommend individualized care or treatment for blood lead levels between 10 and 15 (CDC, 4). For children with a BLL of 20 or greater, or a persistent level (multiple tests over time) between 15 and 19, the CDC recommends individualized case management and environmental interventions to eliminate sources of the lead poisoning. Rhode Island has, generally, followed these recommendations. While blood lead levels of  $10\mu\text{g}/\text{dL}$  or higher are considered lead poisoned, children with a BLL of 20 or higher, or children with a persistent<sup>7</sup> level of 15 to 19, are defined as “significantly lead poisoned<sup>8</sup>.”

In the time period covered by this evaluation<sup>9</sup>, HEALTH responded to reports of lead poisoning in various ways, depending upon the level and the child’s location. Parents of children with incident, or first time, blood lead levels from 10 to 14, regardless of residence, were mailed an informational packet describing lead poisoning and its prevention. Children with an incident BLL of 15 to 19 (non-persistent) were, regardless of location, referred for “preventive” home education visits. Nurses from a Visiting Nurse Association (VNA) under contract with the Family Outreach Program of HEALTH, would receive the preventive referrals. Three different VNAs were issued the referrals, depending upon the residence of the poisoned child, although the VNA of Care New England, whose territory included the metropolitan Providence area, received the bulk of the referrals. The one or two home visits would consist primarily of a visual inspection for lead, lead education and information on the control of lead hazards, as well as

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<sup>7</sup> Two blood lead level tests more than 90 but less than 365 days apart, both in the range. This definition was added to Rhode Island’s regulations in June of 2001.

<sup>8</sup> This misleading terminology is from the original state lead legislation. Amendments to the Act in the summer of 2002 offered the term “Environmental Intervention Blood Lead Level” to replace “Significantly Lead Poisoned.”

<sup>9</sup> In the summer of 2002 and in January of 2003, substantial changes were made in the case management system. However, these are not discussed in this evaluation, which covers from 1999 to 2001.

the importance of lead screening and referrals to other agencies to address non-lead social or family issues.

The follow-up for children who were significantly lead poisoned was substantially more complicated. Children who lived outside of the Providence “Metropolitan” area<sup>10</sup> were also referred to the VNA assigned their geographic region by the Family Outreach Program. Nurses handling the follow-up for significantly poisoned children were required to provide a minimum of two home visits, focusing on lead education, lead screening, referrals for additional support, and were also required to perform a developmental assessment. The activities to be performed by the nurses were governed by a contract between the VNAs and HEALTH. The VNAs were paid on a fee-for-service basis per visit, either directly by HEALTH or through Medicaid reimbursement.

Children residing within the Providence area who were significantly lead poisoned were referred to the HELP Lead Safe Center (HLSC)<sup>11</sup>. HLSC was the first, and until recently, the only Comprehensive Lead Center (CLC) certified by the state’s Medicaid agency, the Department of Human Services (DHS). As governed by DHS certification standards, HLSC was required to provide intensive lead education over a number of home visits, conduct developmental assessments, and provide referrals to other agencies for additional support. Services were to be provided as long as the family required to achieve the goals, generally expected by DHS to be a period of 3 to 6 months. Additionally, Medicaid enrolled children in the RIticare/Riteshare programs receiving lead center services were eligible for a window replacement program financed by DHS, although this program has been under utilized for a number of reasons and is not considered in this evaluation. HLSC was paid a fixed monthly rate for each Medicaid enrolled child receiving services. HLSC did not receive payment from DHS or HEALTH for Non-Medicaid enrolled children.

(Additional information on some specific requirements for elements of case management are included throughout relevant sections of the evaluation. The detailed specifications for the services provided by both the VNAs and HLSC can be found in their respective contracts, as referenced in the Reference section.)

All children with significant lead poisoning, regardless of case management agency assignment, also received Comprehensive Environmental Lead Inspections from licensed inspectors under contract with HEALTH. When lead hazards are identified within the child’s home, HEALTH staff conducts enforcement actions, and if necessary the property owner can be prosecuted in state or local court to force compliance. Both the case managers and nurses are expected to assist the inspectors in gaining access to the family and to explain the results of the inspection.

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<sup>10</sup> Defined as: Barrington, Bristol, Central Falls, Cranston, East Providence, Johnston, North Providence, Pawtucket, Providence, Warren, and Warwick.

<sup>11</sup> Children from other areas of the state could be seen by HLSC, but referrals were not sent by HEALTH for children outside the service area, as defined by DHS.

## Methodology

Work on this evaluation began in July of 2001. A mini-literature review of information on case management for lead poisoned children and informal discussions with individuals involved in RI's system were conducted that month. A proposed outline of what areas this evaluation would encompass was generated. Discussions within HEALTH as to the direction and feasibility of the evaluation occurred in August of 2001. On September 5<sup>th</sup>, an outline of the evaluation was presented to Mary Jean Brown (Of the Harvard School of Public Health) and Pat McLaine (of the National Center for Healthy Housing), two national experts in lead poisoning case management, for their feedback and suggestions. A revised outline was presented to HEALTH's partners in case management (RI Department of Human Services, HELP Lead Safe Center, and the Visiting Nurses Association of Care New England) on September 17<sup>th</sup>, 2001. Substantial feedback from both the meeting of the 5<sup>th</sup> and the 17<sup>th</sup> was incorporated into the design of the study, although the final design and methodology was the responsibility of HEALTH staff<sup>12</sup>.

## Parental Survey

In order to assess accurately elements of the case management process, it was clear that a review of administrative records alone would not be adequate. Most outcome measures, such as changes in blood lead levels, can be obtained from reviews of appropriate data sources. However, process measures, including convenience, satisfaction, customer service, etc, would require additional data collection. To accomplish this within a reasonable timeframe, we utilized a telephone survey of the parents of children who had been offered case management services.

The survey was developed with the intention of obtaining a fairly comprehensive overview of the case management process and to be applicable to a broad range of situations. To achieve this, the survey was "branched," asking a different series of questions depending upon responses to the initial questions. For example, parents who refused case management services were asked about their reasons for refusal as well as some comparative questions about lead poisoning prevention, while parents who accepted services were asked about their perceptions of the services. While the entire survey is 56 questions, the most any one family could be asked is less than forty, with most families being asked to respond to approximately thirty. To help minimize bias introduced by sampling only families comfortable with speaking English, the survey was also translated into Spanish. The final versions of the survey are included as Appendices I and II.

Prior to actual administration of the survey, a "focus group" of parents was convened in early December of 2001 to ensure the understandability of the survey. The parents were invited to come to the HELP Lead Safe Center in Providence in the evening and were provided refreshments and a small stipend for their participation. Facilitators went through the survey with the parents, verifying both the applicability and understandability of the questions. Following the focus group, additional parents were contacted by phone to further test the understandability and appropriateness of the questions. Based upon the input from our test groups, several questions were substantially re-worded, additional responses were added for others, and one question was removed.

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<sup>12</sup> Of course, any errors and omissions are our own.

Our bilingual parent consultant was trained by our Education and Outreach Coordinator and our Epidemiologist in the proper administration of phone surveys. The parent consultant called families between December 2001 and March 2002 from randomized lists of families who were offered services from October of 1998 to December 2001. Over-sampling of known Spanish speakers and those who received services from the VNA was conducted to obtain a larger number of such respondents. Obtaining correct phone numbers proved to be a substantial challenge. In addition to information in HEALTH screening records, phone numbers were obtained from KIDSNET data and phone directories. However, families that could not be located were necessarily excluded from the survey, and this may bias the results if families with certain traits or viewpoints were more likely not to be reachable on the phone. The vast majority of calls were made during normal business hours, however, follow-up calls when the family could not be reached were made in the evening and on Saturdays. In total, 91 families were reached and offered participation in the survey. Thirteen families refused to participate in the survey. Of the remaining 78, 39 (50.0%) received services from the HELP Lead Safe Center, 33 (42.3%) received services from the VNA, and 6 (7.7%) received services from both agencies. Twenty one (26.9%) of the surveys were conducted in Spanish.

Following completion of the interviews, survey responses were entered into an Access database for ease of analysis. Multiple choice response items were summarized and stratified by agency and language. The results appear in the relevant sections of this document. Open response questions were reviewed and summarized. The interpretations appear in the relevant sections of this report.

## Data Analysis

All data not collected from the parental survey was taken from existing data sources available to the Lead Program at the Department of Health. Since late 1998, a comprehensive database of all children referred for case management services as a result of a significantly elevated blood lead level has been maintained. Part of the "STELLAR" system, this particular table, known as "PB\_OUTREACH," contained information on the child, the agency referred to, date referred, outcome of the case management, the date the case was closed, and to which additional agencies the child was referred. For the purposes of this evaluation, first time referrals between 1/1/1999 and 12/31/01 were used. Only the first referral for a particular child was used to avoid potential confounding from the fact that second-time referrals may proceed through case management in a different way since the parents may only require reinforcement of messages rather than a full complement of services<sup>13</sup>. An exception was made, however, in a handful of cases where the child was initially referred to the wrong agency, and the case was rapidly reassigned to the correct agency.

Additional information from the study was collected from the program's database of Blood Lead Level tests. Using an identifier common to both the PB\_OUTREACH and BLL system, all blood tests for children included in the data analysis were identified. Due to a data problem, six children with qualifying PB\_OUTREACH records did not have corresponding BLL records. These children are excluded from all analyses requiring linkage to the blood lead records. The usage of blood lead tests varies depending upon the analysis conducted, and information on which tests are used appears with the results for each analysis. In all cases, however, the date of the blood test is determined using an algorithm to avoid excluding data with some missing information. In general, the date the sample was drawn from the child is used as this best represents when the child had the reported blood lead level, and it best

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<sup>13</sup> A similar argument could be made for excluding poisoned siblings of previously poisoned children, but unfortunately these cannot be readily or accurately identified from HEALTH data sources.

corresponds to when the parent received a service. In limited cases where the sample date was unknown, the date the sample was received by the laboratory or the date the result was reported by the laboratory were used in that order of preference.

Several analyses also required the use of data on environmental lead inspections. This information is also stored in a "STELLAR" table, known as "PB\_INSPECT." While all children who received case management referrals for significantly elevated blood lead levels should also be offered an inspection of their residence, due to data entry errors, several children could not be linked to matching inspection records and were excluded from the study. Records were selected from PB\_INSPECT to identify the inspection that was concurrent with the referral for case management or which resulted from the same elevation of blood lead level. In cases where the first inspection concurrent with the case management referral indicated that the child had moved, the next inspection referral, at the child's new address, was used. In some cases, the inspection greatly pre-dated the case management referral, indicating that another child was poisoned at the property prior to the identified child, or that the child was previously poisoned prior to the implementation of the outreach tracking system. These cases were excluded from further analysis.

Finally, information on referrals for "preventive visits" for children with a single venous test of 15 to 19 is not included in PB\_OUTREACH. Children receiving these services were identified using the blood lead level database to identify children who would have been referred. Follow-up blood lead levels were the only outcome considered and were also pulled from the blood lead level database.

## Evaluation of Case Management Process

This section of the evaluation will consider the process of case management and client satisfaction with the process. The process of case management, that is enrolling cases, engaging the client, and discharging the client, is crucial to obtaining successful outcomes. Obviously, if clients are never enrolled, they are not going to benefit. On a more subtle level, however, clients who don't develop a bond with their case managers or who have a difficult time communicating with the case managers because of a language barrier, may very well experience diminished outcomes. Understanding the successes and failures in the process of case management is an essential prerequisite to understanding the outcomes of case management.

### Capturing Cases

In most situations, referrals for case management are made by the Department of Health upon receiving electronic notification of a blood test with an elevated lead level. In some cases, the family will learn about the impending referral from their child's physician, who should receive both the lab result and notice of the case management referral prior to the case management agency. However, in a substantial number of cases, the case manager is the first to both inform the family about case management services and about the elevated blood lead level.

The first task for the case manager then necessarily becomes finding and engaging the family in order to secure consent to the services. Physically locating the family may prove to be a challenge if the address or phone number provided at the time of the blood test is out of date or incorrectly recorded. Good case management requires good detective skills, utilizing a variety of resources to locate the referred family. Case managers also must be available at hours compatible with working parents in order to successfully locate and contact some families. While the benefits of accepting the case management services may seem evident to health providers, case managers may need to gently encourage parents, who may, for any number of reasons explored below, not be interested in the services, to participate. Good case managers, while respectful of the family's right to refuse services, will sell their services in a way that appeals to the family and address fears, stated or not, that the family may have in accepting the services.

### Number Located and Number Accepted or Refused Services

A total of 744 first time referrals for a significantly lead poisoned child were issued between 1999 and 2001. Eighteen cases were soon closed for administrative reasons (wrong service area, child overage, etc) and excluded from future counts, leaving a total of 726. Over three-quarters of the referrals (553 or 76.2%) were provided to the HELP Lead Safe Center. The remainders were referred to the Family Outreach Program, serviced by a Visiting Nurse Association. The VNA of Care New England took 160 significant cases (22.0%) over the three years, and the Visiting Nurse Health Services (of Newport) took the 13 remaining cases (1.8%).

There were 38 cases where the family could not be located (5.2%). This accounted for 24 of the HLSC cases (4.3%) and 14 of the VNA cases (8.1%).

A total of 92 cases (12.7%) were not serviced because the parent would not accept the services. In two of these cases, the parents essentially wouldn't even open the door, and in the other 90 the services were briefly described and the parents actively turned them down. HLSC had 80 refusals (14.5%), while the two VNAs had a combined 12 refusals (6.9% - 10 for VNACNE and 2 for VNHS). (See chart "Disposition of First Time Referrals for Significant Lead Poisoning" in Case Closure section of this chapter.)

Thus, in total, 130 cases referred were not serviced, for an overall capture rate of 82.1% (596 cases). The capture rate for HLSC was 81.1% (449 cases) and for the two VNAs was 85.0% (147 cases).

In the parental survey, 14.3% of the families polled told us that they decided to refuse the case management services before receiving a single visit (The survey deliberately oversampled refusals to obtain information on why families refused). The refusal rate reported by parents receiving "preventive" (single 15 to 19) visits from the VNA was 20%. For significant lead poisoning visits from the VNA the refusal rate was 23.1%, and for HLSC it was 5.3%. This over-sampling of refusals from the VNA and under-sampling of HLSC refusals was not intentional.

While the recent recommendations for case management from the CDC recognize "client identification and outreach" as the first step in the case management process, these do not provide recommendations on how to do this, nor provide benchmark for comparing capture rates (CDC, P.5).

### **Reasons for Refusing & Interest in Alternative Services**

When asked as part of the parental survey why case management services were not accepted, the most common response was that the respondent did not recall being offered services. It's possible that these families were some of those who were not locatable by the case management providers. However, it is also possible that many of these families, having not received services, have simply forgotten the relatively non-eventful phone call where the services were offered. Of course, any of number of other explanations can help to explain this, such as someone else in the family was offered and refused, or possibly that their case really was "lost" and either was never referred by HEALTH or never acted upon by the agencies. Given the large number of "never offered," it would seem that this last possibility is unlikely.

Another response received multiple times was that something about the child or the environment had changed, making the services, at least in the parent's mind, unnecessary. Two respondents noted that their child had a re-test and the level had already dropped. Two other respondents noted that they had moved the child out of the environment they believed to be causing the problem (one family moved, another child stopped staying at grandma's house). Finally, the remaining parents simply stated that they "didn't want" services, without elucidating their exact concerns and objections to the program.

When the families who indicated they had refused services were asked if they would have liked an alternative service, the majority responded that they would not have. Several of the respondents noted that their pediatricians had provided them with brochures and they felt they had adequate information to address the problem. Another indicated that they had seen a video on lead hazards and felt this was adequate. Two respondents indicated that they couldn't think of services they would like, but weren't sure of what services were available. Of the respondents who would have liked additional services, most were not specific as to what services they would have preferred. Two of the respondents who

would have liked services were ones who had previously indicated that they could not recall ever being offered services. The only specific response from parents in terms of alternative services was a desire for services to help them with landlord/tenant issues. One parent noted that after his/her child was found to have a high lead level, his/her landlord did not treat him/her well, and would have liked assistance in dealing with the landlord.

While these suggestions provide a starting ground, the survey failed to reach enough families who had refused services to yield a complete understanding of why these families refused or what alternative services would work better. Given the critical importance of this information, further research will be necessary to help understand the refusal problem and provide insight into methods for increasing participation.

### **Delivering Services**

Once families are enrolled in the program, the case managers must be able to successfully deliver the services to the families. Both HLSC and the VNAs utilize a home-visiting model for their case management services, sending a staff member to the family's home to provide educational information and point to actual lead hazards in the house. In this section, we consider the timeliness of these visits, the convenience of the visits, and the potential for language barriers to interfere with the conveyance of information.

### **Time Taken to Schedule/Receive Initial Home Visit**

Parents were asked in the survey approximately how long after they learned about the high lead level did the case manager call to schedule an appointment. This question attempted to get at the length of time for the case managers to schedule an appointment upon receiving the referral, for which there was not data to evaluate directly. However, keep in mind that the referral may not have been generated for some time after the doctor received the notification, and there is likely to be substantial variation in how long doctors' offices would take to notify the parents of the high blood lead (if they ever notify the family).

Despite the limitations of the question, respondents were relatively uniform in their answers. The plurality of respondents indicated that they received a phone call from the case management agency within a week of learning about the child's lead test (51% of HLSC clients, 53% of VNA's preventive visit clients, and 45% of VNA's significantly poisoned clients). The next most common response was within 3 days (17% for HLSC, 13% for VNA preventive, and 27% for VNA significant), followed by within two weeks (8.6% for HLSC, 6.6% for VNA preventive, and 9% for VNA Significant). A total of only seven respondents indicated that it took more than two weeks for them to receive the phone call after learning about the elevated blood lead levels.

Parents were then asked how long they had to wait to actually receive the home visit after receiving the initial contact from the case management agency. (The total time, from learning about the EBL to receiving the first visit was calculated and reported to the parent as a check on the two questions – if it sounded too long or too short, parents were asked to clarify one or both of their answers.) The plurality of responses indicated that an appointment was available to the family in less than a week or less than 3 days (52% for HLSC, 54% for VNA preventive, and 57% for VNA significant). The next most common response was within two weeks (26% for HLSC, 15% for VNA preventive, and 14% for VNA significant),

with a handful of respondents indicating that they had to wait longer than two weeks. Combining these responses with the responses for the length of time taken before being contacted by the case management agencies shows that the plurality of cases would have had their first home visit within two weeks of when the parent first learned about the elevated blood lead level, with many more being done even more quickly. Almost all of the cases would clearly have been initiated within a month, and only a handful would have extended beyond a month from recognition to the initiation of services.

Assuming that the case managers are reaching families shortly after they receive the referrals, it would appear that the majority of families are receiving prompt visits as determined by the recent CDC recommendations. Children with levels of 20 to 44, the most common significant referral, should have an initial home visit within a week of referral, and children with a persistent 15 to 19 should have it within 2 weeks (CDC, P. 6). Children with levels above 45, which may require hospitalization, are recommended to have the initial visit within 24 to 48 hours (*Ibid.*). These cases, which were not adequately represented in the survey, are handled as emergencies by HEALTH, and subject to a different protocol ensuring there is immediate assignment of a case manager.

### **Convenience of Appointment Times**

With near unanimity, the respondents to the survey felt that the times the case managers were available to meet with them were convenient. Only two respondents indicated otherwise. One, an HLSC client, noted that he or she would have preferred earlier or later appointments, but the case manager was really busy and had to meet at times convenient for the case manager. The other, a VNA client, indicated that he or she would have preferred an appointment later in the evening. Given the overwhelmingly positive response, however, it would appear that the case managers are doing an excellent job of making themselves available at times that are acceptable to the family.

### **Appropriate Language**

Parents were queried as to whether or not they had any problems communicating with the case managers as a result of language. Nearly all of the respondents indicated that they had no language barriers in communicating with their case manager. Of the three who indicated a language barrier, two spoke a language other than English – one spoke Cambodian, and the other spoke Creole. The English speaker did not clarify what language barrier they were experiencing. The other two both indicated that they had interpreters who helped them to understand the case manager.

It should be noted, however, that the survey itself was administered only in English and Spanish. It is possible that those who may have experienced substantial language barriers with their case manager may have also been excluded from the survey as a result of a language barrier.

### **Relationship Between Client and Case Manager**

Maintaining a positive relationship with the client is an essential component to superior case management. Clients who do not like or distrust their case manager are not only more likely to withhold information that may help with treatment, but may also discount or ignore important educational

messages delivered by the case manager. Additionally, those who have a positive relationship may be more willing to accept needed services in the future and possibly even advise friends and relatives to do likewise. While it is difficult to assess the quality of the client/case manager relationship, in this section we explore some indicators of this, namely the perceived ease with which the client could reach the case manager, the level of courtesy and respect provided by the case manager, and whether or not the client perceived the case manager to be helpful.

### **Ability to/Ease of Contacting the Case Manager**

One of the keys to a successful client/case manager relationship is the ability for the client to contact the case manager to discuss any concerns with relative ease. Parents were asked if they knew how to get in touch with their case manager if they needed to. All but three respondents indicated that they knew how to reach the case manager. One of the three had previously stated there were language barriers in communicating with their case manager. All of the three also indicated that they never called their case manager, which is not surprising.

The parents were also asked how long it took to get questions answered when they called their case manager. The plurality of respondents indicated that their questions were generally answered immediately when they called. Others who called with questions reported having their questions answered when someone called back, mostly within two days, and a handful reporting waiting more than two days for a return call. No one reported having to call multiple times or never receiving answers to their questions. Several respondents noted that they never called their case manager. In fact, the majority (71%) of those receiving preventive services from the VNA never called. For the families of significantly poisoned children, the numbers not calling were minimal.

### **Case Managers Courteous and Respectful**

In order for the case managers to have a meaningful impact with the family, the parent must have a level of trust and respect for the caseworker. This is not likely to occur if the caseworker does not treat the family with dignity and respect. To assess this, parents were asked if their case managers were courteous and respectful. With a lone exception, all respondents classified their case manager as "Very Courteous and Respectful." The one exception was a single HLSC client who found her case manager to be "very discourteous and disrespectful" and later reported in a free response question that she "didn't get along" with her case manager, apparently in part because the case manager told the client "there was no lead<sup>14</sup>" in her house. Given the near unanimity of response of the "very" option, however, it is clear that the professionals at both agencies are treating their clients with a great deal of respect and courtesy.

### **Perceived Utility of Case Managers**

One important measure of case management success is whether or not clients found the services to be useful for them. Even if case managers offer good advice, if the clients don't perceive it as useful and fail to implement it, little positive can come out of the interaction. To assess the clients' perceptions of the usefulness of their interaction with the case manager, we asked parents both of their general

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<sup>14</sup> A review of the environmental inspection record showed this to be a rather unusual case... And at some point, it was believed that the house was lead safe.

perceptions of the utility of case management and specific, open ended questions as to what was and was not useful for them.

Overall, the parents found the case management services to be useful. The vast majority reported that the case manager was “very useful” in helping to protect their child ( 90% for HLSC, 86% for VNA preventive, and 57% for VNA significant). Only one respondent each reported their case manager to be “somewhat useless” or “not at all useful.” The same individual who found his or her worker not at all useful was the same individual who found the worker to be very disrespectful and discourteous. The individual who reported his or her VNA nurse to be “somewhat useless” in other responses indicated that he or she felt that nurse told him or her that the house was too dirty and that they should move, but not much else. Given the extremely high percentage of those who found the experience to be very useful and the near unanimity of useful or somewhat useful responses, the case managers are doing a very good job of providing guidance in a way that the parents feel is assisting them.

When asked specifically about what the case manager did that was particularly helpful, parents gave mostly general responses. The two largest themes to emerge were that parents liked receiving support and information. Many parents noted that their case manager provided reassurance or told them that the poisoning was not their fault and made them feel comfortable. Respondents also frequently noted that they found the “information” to be helpful generally, with several also noting that the brochures left behind were helpful. Those who identified specific elements of “information,” most frequently cited cleaning and nutritional tips as being particularly helpful. Along a similar line, several of the parents noted that their case manager told them where they had to clean and where exactly the lead in their home could be found, which was helpful to the family. Four families noted that information on landlord/tenant issues or having the case manager speak to the landlord was helpful. Three noted discussions relating to child development to be particularly helpful. Two parents responded simply “everything” and two noted that the accessibility of the case managers or their ability to ask questions at any time was particularly helpful. Three respondents didn’t have a response that was of something helpful – the individual who previously described the services as “useless” did not find anything to be helpful, another said his/her case manager just came in the house and looked around, and the final one said that the family had moved to a lead safe apartment prior to the first visit, and therefore there wasn’t much to do.

As part of the survey, parents were also asked what the case manager did that was not helpful or that was perceived to be a waste of time. Quite impressively, all but five respondents could not think of anything that fit this category. Two of those with a suggestion were the same individuals who did not offer anything positive as described above, both saying the case manager did nothing more than just come in and look around. One of the others suggested that information was repetitious, and they were told the same thing many times. Another parent thought that the case manager provided inconsistent advice. The final parent felt that he or she was being “checked up” upon by the case manager.

Parents also had few suggestions as to other services that they would have liked to receive or for other things the case manager could have done to help. All but six parents could not think of additional services. Many of those who could not think of anything took the opportunity to say how “thorough” or “excellent” the services were. The few that offered suggestions for additional services each had a different suggestion: one wanted information on developmental effects and the threshold of effect for different blood lead levels, one was interested in meeting other families dealing with lead issues, one was looking for more action to get the landlord’s cooperation, one would have liked recommendations

for a lead contractor, one complained about making apartments lead safe instead of lead free, and the final suggestion was for more follow-up after the first few months.

### Case Closure

When the case management “program” has been completed, the family needs to be discharged and their case closed. Normally, when the case manager has worked with the family to accomplish the items in their case management plan, the case manager will inform the family that it is time to close the case. In some circumstances, however, the family may decide they have received all of the services they need or the family moves without ever informing their case manager of a new location, and the case must be closed as incomplete. Ideally, the percentage of cases closed as incomplete should be minimal.

There are currently widely varying definitions of what criteria should be utilized for closing a case and terminating case management services. Recent CDC recommendations call for cases to remain open until “...environmental lead hazards have been eliminated, the child’s BLL has declined to below 15µg/dL for at least six months, and other objectives of the plan have been achieved...” (CDC, P.7). This definition provides both quantitative (BLL under 15 for six months, hazards eliminated) and qualitative measures (plan completed) that must be meant. With a case open, by definition, for a minimum of six months, quite possibly substantially longer, this is an extremely difficult standard to meet and would result in a huge increase in the case load of case management agencies.

Currently, none of the case management providers in RI use such a strict criteria with a clear quantitative metric. HELP Lead Safe Center is required to abide by standards developed by the state Department of Human Services (DHS) which provide for case closure when “...the FCP [Family Care Plan] has been implemented, the family is stable, the lead level is going down, the family is receiving all needed services and CLC [Comprehensive Lead Center] services are no longer needed” (DHS, P.13). While noting that the lead level should be going down, there is no clear definition of what qualifies as proof of a declining lead level. It is also the expectation of DHS that these services be completed within three to six months, a time frame shorter than that recommended by the CDC (*Ibid.*). Besides the provision of two home visits and completion of required education, there are no specific guidelines for closing the cases of children referred to the VNAs (HEALTH, P.20-21).

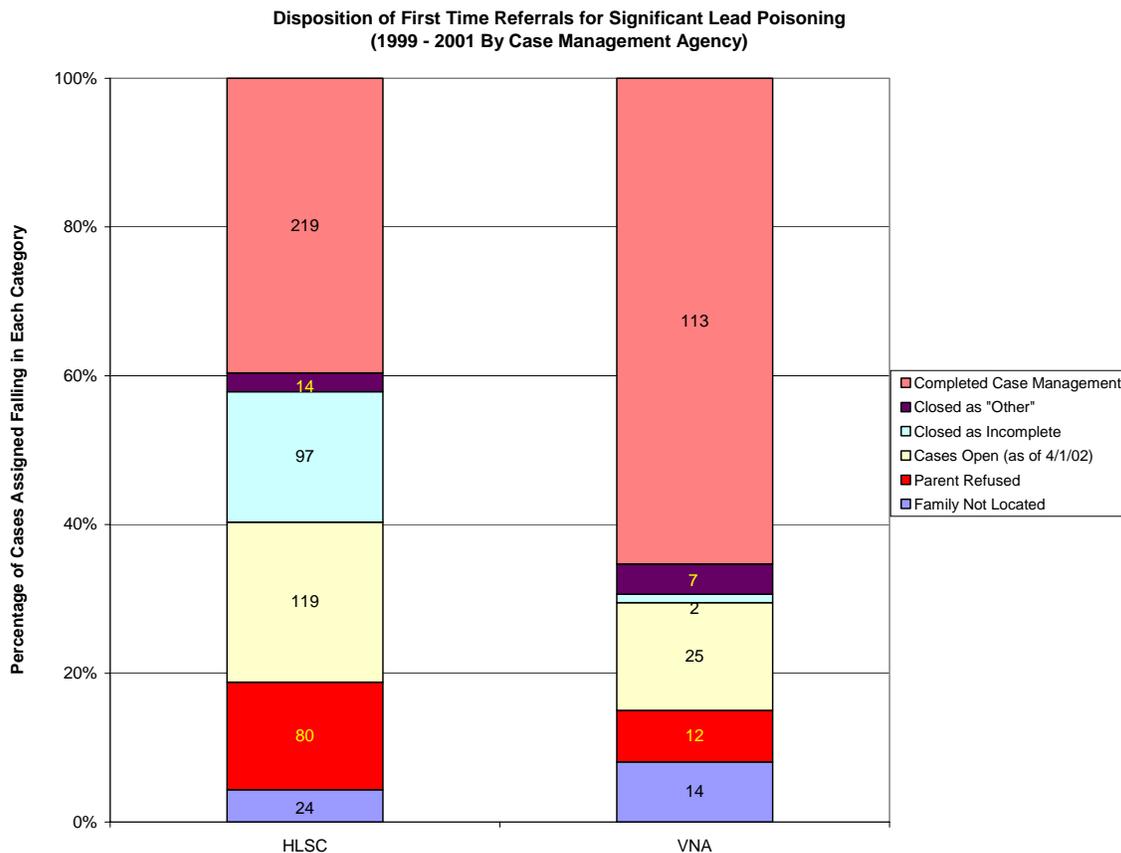
This section will report on the reasons for case closure, information on why parents chose to dropout of case management, and parents’ perception of the adequacy of the number of visits they received. The Outcomes chapter of this evaluation goes into length of time cases were open, blood lead levels at the time of case closure, and other metrics which would aid in understanding the family status at the time the case was closed.

### Origin and Reason for Case Closure

Of the 596 cases that were successfully opened in 1999 to 2001, as of April 1st 2002, 144 cases (24.2%) were still open according to DoH records, although there may be some lag in record updating. One hundred and nineteen of the open cases were with HLSC (26.5% of their total) and 25 with the two VNAs (17.0% of their total). Looking only at the closed cases, 332 total were discharged from case management as having had all services completed (73.5%), and 99 were closed after the parent

requested to stop receiving services or was lost to follow-up (21.9%). The remaining 21 cases were closed for "other" reasons (4.6%). Amongst HLSC clients, 219 were discharged from outreach as being completed (66.4%), 97 were closed after the family was lost to follow-up or the parent asked to stop (29.4%), and 14 were closed for "other" reasons (4.2%). Data for the VNA may not accurately reflect the differences between families who ask to stop receiving services versus those who are normally discharged. Amongst the VNA clients, 113 were discharged from outreach as being completed (92.6%), 2 were lost (1.6%) and 7 were closed for "other" reasons (5.7%). (See chart next page).

In order to assess who dropped out of case management as opposed to who was terminated by the case manager, parents were asked in the survey if they requested to stop receiving services, if their case manager discharged them, or if the case manager and the parent jointly decided to stop the services. The plurality of respondents indicated that their case manager discharged them (44%) followed closely by the choice of it being a joint decision to stop the services (40%). Only four parents indicated that they requested to stop receiving services. While it would appear that the number of dropouts was underrepresented in the survey, it is possible that parents who responded that it was a "joint decision" might have been classified as incomplete by the case managers. To assess the reasons for drop-outs, we asked those who indicated they requested to stop why they requested to stop receiving the services. One respondent said she felt she was all set, one said the family pediatrician was providing the follow-up instead, one said she did not get along with the case manager, and the final said that he or she was not sure why, he or she just never called the case manager back.



### **Comfort Level with Number of Visits Made**

By and large, parents were satisfied with the number of visits that they received from their case managers. When asked if more or fewer visits would have been better, or if the number received was good, 87% of the respondents indicated that the number of visits they received was good. Only one individual responded that there were too many visits, the same individual who found the whole experience to be useless. A total of 6 parents would have liked to have received more visits from the case managers. There were no differences by case management agency. One parent also added that instead of home visits, phone conversations with the case manager were particularly useful and would have liked more phone calls instead of visits.

## **Evaluation of Case Management Impact**

This section of the evaluation seeks to measure the impacts of case management. In other words, what changes occurred as a result of the interventions provided by the case managers? Did the child's blood lead level go down? Was the family able to apply the information taught by the case manager? Answering such questions is essential not only in order to judge whether the investment in case management services is well spent, but also to determine if poisoned children are indeed being adequately helped.

Addressing questions of the impact of case management provides many methodological challenges. The single largest hurdle is finding an appropriate comparison to make – in other words, to what benchmark do you hold the outcomes found. As a retrospective evaluation utilizing administrative records, this analysis lacks the rigor of a well-designed study with a formal comparison group. It's important to recognize that while some comparisons are drawn between the outcomes associated with families receiving services from different case management agencies, or between those that completed case management and those who did not, these comparisons are far from perfect, and in many respects may be comparing dissimilar groups. Children are primarily assigned to case management agency on the basis of geography, and other factors associated with geography, including poverty and prevalence of old housing may confound the relationship between case management agency and outcomes. Families who refuse case management may indeed have more resources or live in different areas than those who accept case management, and this may make comparisons between the two groups potentially troublesome. In a formal study, these factors could be statistically controlled for, however, the necessary information is lacking in the administrative records and thus the impact of potential confounding in this analysis cannot be assessed.

### **Receipt of Appropriate Follow-up Care**

Children with identified lead poisoning require continuing medical care and potentially additional non-medical services beyond those provided by the case management agency. While the precise medical care required varies upon the extent of the poisoning and the individual child's needs, some elements, particularly continued blood lead testing, are universally recognized as essential. The actual provision of the medical care is outside the scope of services expected from the case management agencies, however, case managers should be involved in assisting in the coordination of care for the child. In addition to coordinating care, case managers can teach parents about the need for appropriate follow-up care and assist parents in overcoming barriers to having blood tests performed. This section of the evaluation will consider the impact case managers had in educating parents about follow-up care, ensuring that their clients received needed care, and how they referred to other agencies to provide additional services.

### **Parent's Awareness of Need for Follow-up Tests**

One of the clearest elements of appropriate follow-up care for an elevated blood lead level is continuing lead tests. Obviously, cooperation of the child's primary care provider is key, as only a practitioner can actually order the blood test. However, it is essential that the child's family recognize the importance of continuing screening and continue to comply with doctor's orders or potentially to even remind the doctor of testing needs. The case managers from both agencies are expected to discuss the importance of screening with their clients.

To assess the degree to which parents absorbed information provided (if any) by the case managers about screening, the survey asked if the case manager had ever discussed how frequently the child's blood should be retested for lead. Thirty-seven of the respondents (71%) indicated that their case manager did talk to them about the frequency of screening. Ten parents (19%) indicated that they were not told about recommended frequencies, with the remainder unable to recall if they were or were not. There was a slight difference between the case management agencies, with more HLSC clients not recalling learning about frequency (21% to 15%).

### **Parental Perception of Ease of Having Child Tested for Lead**

Parents were also asked to identify how easy it was for them to have their children screened for lead. While this is largely outside the control of the case managers, it is possible that it could reflect assistance offered by the case managers to help get the children screened, and at the very least indicate a need for additional services should many parents whose children are receiving case management find there to be substantial barriers. Fortunately, two thirds of the respondents found that having their children tested was very easy, and an additional 13% found it somewhat easy. Fifteen percent found it somewhat difficult, with a single parent finding it very difficult to have his or her child tested. There were no substantial differences by case management agency.

When those who said it was somewhat or very difficult were asked why it was difficult and what could have made it easier, most responded that it was traumatic for the child. All but two responses mentioned something about the actual process of drawing the blood from the child, such as the child crying a lot, having to hold the child down, or the child not liking it. There were no suggestions offered, however, on how to improve this. Two of the parents mentioned getting to the laboratory as one of the difficulties. Two individuals also mentioned that they had to wait too long for the results of the test, one of them specifically saying that it took three weeks. Finally, one person mentioned that obtaining the lab slip from the doctor was inconvenient.

Parents who had refused the case management services were also asked about the ease of obtaining blood tests since this issue is largely unrelated to whether or not the child received services. By and large, those not receiving case management also found it to be very easy to have their children tested for lead. 17 of the 21 respondents (81%) said that it was very easy, with one parent each responding somewhat easy, somewhat difficult, and very difficult. One parent did not know. The two parents who found it somewhat or very difficult had similar complaints to those who did receive case management, namely that it was traumatic for the child.

### **Percentage of Children Receiving Follow Up Blood Tests**

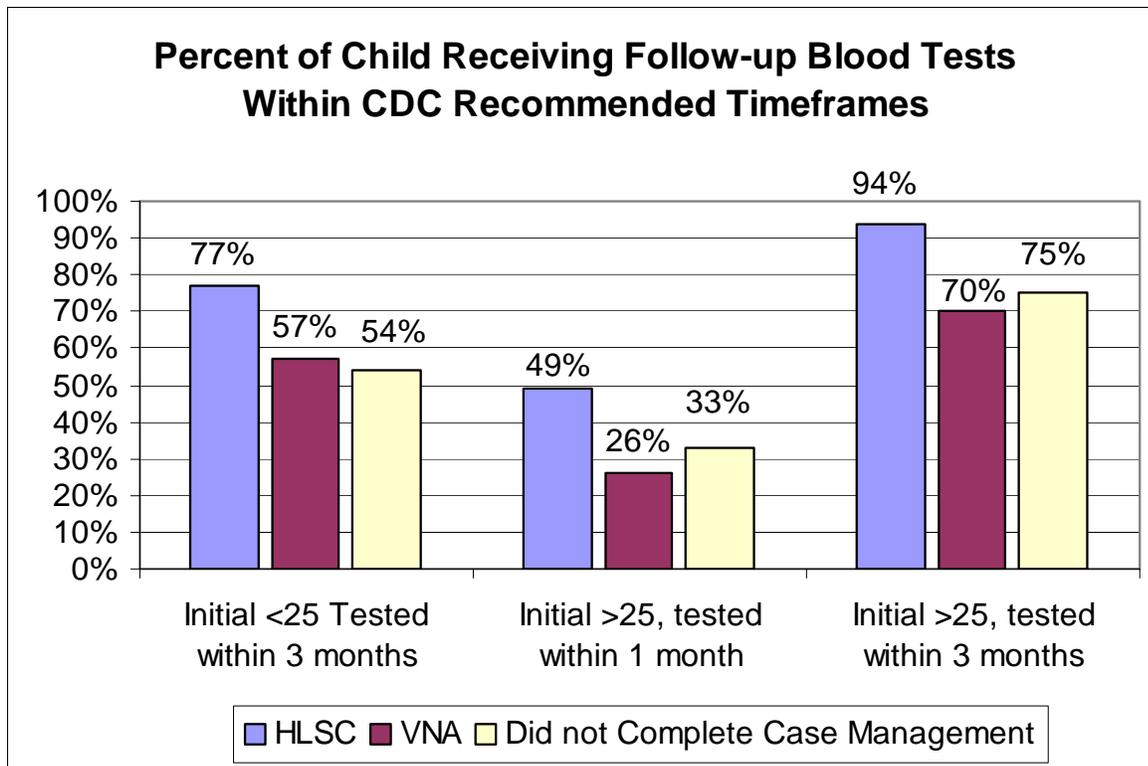
Looking at cases which fully completed case management and had a valid link to blood lead measurements (a total of 330), 255 (77.3%) children received at least one blood lead test during the period the case was open. The median number of tests per child during case management was two. Twenty-five percent of the children received three or more tests during the case management period. Looking only at children serviced by HLSC, however, 97.7% of the children had one or more lead tests during case management. HLSC's affiliation with the St. Joseph Lead Clinic likely plays a role in the high follow-up screening rate for its clients. For the VNA, 37.5% of the children had 1 or more tests

during case management, a result almost certainly a result of the fact that most VNA cases are open less than three weeks. The mean number of tests for HLSC clients during case management was 2.7, with a median of 2 tests. Again, 25% of the children had three or more tests during case management.

Rather than limiting to blood tests while the case was open, another way of looking at follow-up testing is to assess how many lead poisoned children received tests consistent with CDC recommendations. For blood lead levels between 15 and 24, the CDC recommends that children have a follow-up blood test within 3 months. For blood lead levels between 25 and 44, the CDC recommends that children have a follow-up test within a month. (CDC P.51). It should be noted, however, that HEALTH makes no specific recommendations for the follow-up care for poisoned children, including time intervals for follow-up testing. Case managers and treating doctors may not be aware of the CDC recommendations.

Of the 330 completed cases, all but 11 (3.3%) had a subsequent BLL test at some point after the test that caused the case referral. 10 of those 11 were cases referred to the VNA. All eleven cases were also initially referred no later than January of 2001, so all had at least 18 months to have received a follow-up test. The overall median was 51 days from the opening test to the next follow-up test, a figure well within the general three-month window. However, approximately 25% had the first follow-up more than three months later. Breaking it down to the specific blood lead levels, 71% of the children who were referred with a BLL <25 had a follow-up test within 3 months. Only 43% of children with a BLL  $\geq$ 25, however, had the recommended follow-up test within 1 month. 86% of the  $\geq$ 25 children, however, did receive a follow-up test within 3 months, showing some improvement based upon initial blood lead level. There was substantial difference based upon case management agency. HLSC clients starting with a BLL <25 had 77% tested within 3 months, opposed to 57% for VNA clients. HLSC clients with an initial BLL  $\geq$ 25 had 49% tested within a month, opposed to 26% of VNA clients (with 94% of HLSC, and 70% of VNA clients  $\geq$ 25 tested within 3 months.)

Looking at all the cases that did not complete case management services, 21 cases (7%) did not have a subsequent BLL test after the test that caused the referral. Overall, 62% had a follow-up test within three months, with a median of 64 days. Of the incomplete cases referred with an initial BLL under 25, 54% received the follow-up test within the 3 months. Of the incomplete cases with an initial BLL of 25 or higher, only 33% received the follow-up test within a month, and 75% received the follow-up test within 3 months. Thus, overall, there is a substantially higher retest compliance rate amongst those receiving services than those that did not, especially those that received services from HLSC.



After the close of case management, 289 of the 330 completed cases (88%) have had at least one additional blood lead test, although 6 of the cases have been closed less than year and may not be due for another screening. The median number of tests following closure of the case was 2. The rates were very similar regardless of case management agency (89% for HLSC versus 86% for VNA).

### Referrals To Other Agencies Including WIC

Families who are going through the ordeal of having a lead poisoned child are likely to be experiencing a number of other social or economic stresses. Case management needs to recognize that families burdened with multiple problems are not going to be able to focus all of their attention on lead, and thus referrals appropriate to help the family with a variety of issues are necessary.

HEALTH currently receives data on to which agencies families were referred as an element of HLSC closed case reports. Unfortunately, similar data from the VNA is not currently available, and thus for this section, we can only consider clients who received services from HLSC. Looking only at the cases closed as being completed, 63% of the clients were referred for at least one service. The median number of agencies or programs each client was referred to was 1, and the mean 1.1. Housing assistance was the most common referral, with 51 clients (23%) referred, followed by other (49 referrals, 22%) and Headstart (33 referrals, 15%). Only 30 clients (14%) were referred to WIC, the supplemental nutrition program. Nearly all of the clients should have been eligible for WIC support, however, as being lead poisoned is a recognized nutritional risk by WIC and if the children were enrolled in Rlticare they would be financially eligible for WIC. This metric fails to capture, however, children who may have already been active in WIC prior to the incidence of lead poisoning.

### **Siblings of Poisoned Children Screened**

Siblings of lead poisoned children are at greatly increased risk for lead poisoning. For this reason, it is especially important to ensure that all siblings of lead poisoned children receive screening tests on at least the generally recommended intervals. Unfortunately, it is not possible to utilize HEALTH data to analyze this because there is no way to reliably identify siblings or children who live in the same household, especially if they are not screened. Thus, to assess this, we asked all parents whether or not there were other children under the age of six in the household, and if so, when they had last been screened.

Thirty-six respondents (48%) identified having another child under the age of six in the household. Since some households reported multiple children under the age of six, there were a total of 47 other children identified. Of the 47, 11 were reported to be under 9 months of age, and thus too young to be screened. Of the 36 eligible children, all but three had been reported to be screened, for an overall sibling-screening rate of 92%. One of the three unscreened was from a family who had refused case management services, the other two had received services. Of the 33 screened, all but two were screened within the last year, indicating that 31 (86%) are being screened in compliance with the state regulations.

### **Parents Retain Increased Awareness of Lead Poisoning Issues**

A key element to case management is to provide parents with a better understanding of the causes of lead poisoning and ways to reduce their child's exposure to lead hazards. While education alone without effective environmental intervention is unlikely to have a significant impact upon blood lead levels, education is essential to securing cooperation with the parent and ongoing maintenance of a lead safe environment. This section of the evaluation examines whether or not parents were receiving or retaining information provided by the case manager and whether or not they were taking action based upon the information received.

### **Parents Feel Efficacy**

One of the outcomes of case management should be an increased sense of ability for parents to take action to protect their children from lead hazards. Of course, as long as lead based paint is allowed to generate hazards, parents will not be able to completely protect their children, especially in rental property where there is little control of the environment. However, parents do need to understand what they can and should do to help protect their children.

One of the items we asked parents was "In general, how much do you believe parents can prevent lead poisoning in their children?" While recognizing that a goal of case management should also be not blaming the parent for lead poisoning, we also need to make sure that parents feel as though there is action they can take. Thus, we would hope that few parents would believe that there is nothing they can do to prevent lead poisoning. Of families who did receive the case management services, none responded that there was nothing parents could do. Six (12%) of the respondents felt that there was not much parents could do to prevent lead poisoning, with the remainder feeling parents could somewhat prevent (67%) or completely prevent (21%) lead poisoning. Amongst those who refused

case management services, all respondents felt that parents could somewhat prevent (65%) or completely prevent (35%) lead poisoning.

### **Case Manager discussed what parents can do/they did it**

Case managers largely play the role of educator. Families should be discharged from case management with a better understanding of the problem and its causes. To truly assess the educational value of the case management process would require a more rigorous evaluation system, involving an assessment of parent's knowledge both before and after the fact. To begin to get to this, however, we asked parents what the case manager discussed with them. While not a measure of everything discussed since parents may have forgotten some items, anything parents do recall must have successfully "stuck" with the parents. To begin to see how parents turned knowledge into action, we also asked parents what actions they are still doing. The survey taker was instructed to push the parents for specifics if possible, rather than general statements.

Only two respondents who received case management services were not able to identify some relatively specific discussion with the case manager. The remainder all recalled at least one message from the case manager that would indeed contribute to lead poisoning prevention. Nearly all of the responses received had a component related to the environmental control of lead and leaded dust. This is a very positive finding since the most effective solutions are the environmental controls. Nearly all of the respondents mentioned cleaning as an item discussed. Many specially recalled TSP, and several recalled specific areas the case managers told them to be cleaning, and several mentioned wet cleaning, although one responded "dusting and vacuuming" which are not effective cleaning methods for lead. A handful of respondents also mentioned other environmental controls, such as duct taping peeling paint, maintaining painted services, and two respondents even suggested the case manager felt moving to a safer house would be a good way to protect the child.

Second only to cleaning for most frequently recalled, was nutritional tips. Nutritional changes, while unproven to have significant impact on lead poisoning, are theorized to have some benefits (CDC, 61). Additionally, given the likelihood that lead poisoning and nutritional deficits may share common risk factors, nutritional counseling is one of the recommended components of family based holistic interventions. Many of the survey respondents identified iron supplementation in particular or vitamins generally. A few responded with some specific foods, including broccoli and milk. In addition to changes in diet, many parents reported that the case managers suggested behavioral changes as well, such as increased hand washing or keeping the child from playing in certain areas.

The two cases where the respondent could not think of anything specific simply noted that the case manager had talked to them about prevention or that the case manager had left some pamphlets with prevention information.

A similar question was asked of those who refused case management services, asking what actions they took while their child had a high lead level, as a comparison. Four of the parents offered responses that the lead was not coming from their house, and therefore they took no action. It is difficult to know, however, if this is an incorrect assumption from the parent, or if it is based upon fact (although if it were based in fact, it is not surprising that the number is large in the refused group as they would then not see themselves as needing services). Of those who did offer actions taken, many of the

parents had specific actions that were similar to those parents who had accepted the services. Again, environmental controls were the most common response, with almost all of the respondents indicating some sort of cleaning, and several specifically mentioned TSP. However, two of the respondents responded that they dusted frequently, which if done dry could have increased the child's exposure to lead. Six of the parents, a much higher percentage than in the case management group, noted direct environmental interventions, including painting and window replacement. Unfortunately, it is not known whether or not these interventions were done safely, and if not could, in fact, make hazards worse. Nutritional changes were also frequently noted, with several noting iron supplementation as a strategy. Only one respondent specifically named foods. Behavioral changes were also frequently noted, including hand washing and keeping the child away from certain areas.

To get a sense of whether or not parents continued their strategies for prevention, they were asked which of the previously named prevention activities they still practiced. Approximately three-quarters of the respondents who identified a task are continuing part or all of the practices at the time of the survey. Environmental interventions, cleaning tasks, especially, remained something that most of the respondents recognized as having to be continued. Nutritional changes, however, were only mentioned by about half of the persons who previously had mentioned them. Additionally, several parents mentioned that they were no longer worrying about lead. One parent reported that since his/her child was older and no longer putting things in his/her mouth, the parent was no longer practicing lead controls. Three other parents mentioned that since they moved or since their apartment was now lead safe, they were no longer taking preventive action.

The parents who refused case management services were also asked as to what activities they are continuing to do. As a whole, only about half of these respondents identified continuing activities. Interestingly, however, cleaning and environmental interventions were just as likely to be kept as nutritional support amongst this group. Those that responded that they were no longer doing prevention activities uniformly responded that their dwelling was lead safe and therefore there was no need to keep up controls.

While as a whole those that received services were aware of more controls and continued them longer, there is a need for parents to have a more complete understanding of long-term control, especially the need to continue monitoring lead-safe dwellings so they are maintained that way.

### **Coordination with Environmental Inspection**

An essential element of care for lead poisoned children is a thorough investigation of the child's environment for potential lead hazards. Inspections of children's dwellings and any resulting enforcement are coordinated directly by the Department of Health. The case managers, however, are required to assist the inspector in reaching the family as well as to assist in helping the family to understand the inspection results. To evaluate this, parents of significantly lead poisoned children who both accepted and refused case management were asked about their experiences with the environmental lead inspector sent by HEALTH. Three respondents, two of whom received case management services, could not remember whether or not the environmental inspector was sent to their house, and are excluded in this section.

### Case Manager Helped to Schedule the Inspection

Families receiving case management services were asked if the case manager assisted in arranging a time for the inspector to come, or if they scheduled the inspection by themselves. Seventy-four percent of those who accepted the inspection indicated that the case manager helped them to arrange the inspection. Fourteen percent choose to schedule the inspection on their own, with the remainder noting different circumstances, including the property owner handling the affair.

### Acceptance and Refusal of Inspection

HEALTH's current policy requires the family of the poisoned child to consent to the environmental inspection. While the landlord's permission is neither sought nor required, some parents fear potential (and illegal) retaliation from the landlord and for this, or for other reasons, refuse the inspection. To the extent practical, the case managers are instructed to encourage the families to accept the inspection in order to further the treatment for the child. On the survey, two parents receiving case management services reported that they did not have the inspection performed. One parent said that the case manager was to contact the inspector, and that the parent never heard anymore. Another reported that the case manager advised not to have the inspection done to avoid creating difficulty with the landlord.

Two parents who refused case management services also reported that they did not have the inspection performed. One mother indicated that the child was living at the father's house at the time, and the father did not want the inspection, without elaborating on the reasons. Another parent indicated that the inspection wasn't offered at the apartment where he or she believed the child to be poisoned, and thus turned down the inspection.

Turning to the data, looking at records of children referred to case management with a matching inspection record for the same incidence of poisoning, 100 of the 677 cases (15%) refused the inspection or did not respond to repeated attempts to schedule the inspection. Looking only at those families who accepted, and eventually completed the case management services, 24 of 304 (7.9%) refused the inspection or did not respond. Amongst HLSC clients who completed services, 13 of 211 refused (6.1%) and amongst VNA clients 11 of 93 refused the inspection (11.8%). For those that refused case management, quit in the middle, or otherwise did not complete services, 76 of 373 (20%) also refused or did not respond to the inspection. Those who actively refused case management services up front also had the highest rate of refusal for the environmental inspection, with 38 of 112 such cases (34%).

While it is difficult to sort out the effect of case management from what might be best described as the "cooperation level" of the parents<sup>15</sup>, it is clear that those who receive and complete case management are substantially more likely to accept the environmental inspection. There is still room, however, for further compliance with the inspection, particularly among those who start and then stop case management and especially given the fact that some parents are reporting encouragement to turn down the inspection. Finally, it is also important to recognize that these statistics are only looking at the first inspection offered a family – in many cases additional inspections are offered if the family moves, and these inspections may also be refused.

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<sup>15</sup> In other words, a parent who is generally cooperative is more likely to accept services in general, while someone who is uncooperative, or possibly untrusting of "officials" may be more likely to refuse all services.

### **Case Manager Assisted in Interpreting Results of Inspection**

When asked if their case manager helped them to understand the inspection results, over a third of parents responded, "No." Parents who received services from the VNA appeared to be less likely to have received help, but there are too few numbers to make a reliable judgement.

### **Inspection Performed at Convenient Times**

Overall, parents were satisfied with the times that were available for an inspector to come to their home. Ninety-one percent of the respondents found the times available to be very (74%) or somewhat (17%) convenient. Four percent each found the times available to be somewhat not or inconvenient. There were no comments made as to what time would have been more convenient.

### **Length of Time to Receive Inspection Result**

Parents were made aware of the results of their inspections almost always within a month, and frequently quite sooner. About half of parents who both accepted and refused case management services reported receiving their inspection results within two weeks. Another third received the reports longer than two weeks after, but within a month. One parent reported never receiving the inspection report, and the remainder identified that it took longer than a month. No difference was particularly noticeable been those that did and did not receive case management services.

### **Relationship with Landlord**

At the time their child was lead poisoned, the majority of respondents (59%) told us they were renting their dwelling. An impressive 27% reported that they owned the home, with the remainder living with family or friends. Those who rented, by and large reported they had an excellent (29%) or good (50%) relationship with their landlord before their child was lead poisoned. After their child was lead poisoned, a majority (52%) still reported having an excellent or good relationship with their landlord, although this is a substantial decline from the nearly 80% before the poisoning. The number with a poor relationship increased four-fold from the before to the after question, indicating, unsurprisingly, that lead poisoning can place a significant strain on the landlord-tenant relationship.

### **Measuring Decline in Blood Lead Levels**

A key goal for case management is to lower the child's body burden of lead as much as possible. While the effects of lead poisoning are by and large believed to be irreversible, eliminating the poisoning can prevent further damage. The only measure available to gauge the success of this is the blood lead level for the child. On one hand, the BLL is the measure believed to be most correlated to the actual process of lead induced brain damage – the free lead circulating in the blood is directly proportional to the lead available to cause toxic effects. Utilizing BLLs as an evaluation outcome, however, presents significant problems. Lead stored in the bones of a child with long term exposure can leach out into the blood stream for years after all environmental sources of lead have been removed. Thus, the change in blood lead level may not immediately or consistently across children measure the impact of efforts to eliminate lead hazards or exposures. Blood lead levels can additionally be confounded by the child's age (as for both physiological and behavioral reasons, BLLs tend to peak at around age 30 months and naturally

decline) and the season (for reasons not completely understood, BLLs tend to be higher in the summer than the winter).

This analysis does not attempt to correct or adjust for these potentially confounding variables or other factors, and in addition, lacks a valid comparison group for making authoritative conclusions. The data analysis in this section is presented as a basis for further analysis and to inform HEALTH as to the current outcomes. It is not designed to nor can it provide scientifically valid comparisons between the different services offered or between receiving or not receiving services.

### **Decline in Blood Lead Level**

Of the cases that fully completed case management, 288 had a blood lead test after the closing date. The first test following case closure was used to calculate the decline in BLL. (BLL change prior to case closure is covered in the Case Closure section below). The mean number of days from the blood lead test that opened the case to this first test after case closure was 263, with a median of 237 days. 17 of the 288 (5.9%) had no change in BLL ( $\pm 1 \mu\text{g/dL}$ ). 27 of the 288 (9.4%) had an increase in BLL. The remaining 244 (84.7%) had a decline in blood lead level. The mean decline was  $9.4 \mu\text{g/dL}$  (95% CI<sup>16</sup>: 8.3 to 10.5), with a median of 9 points. HLSC clients had a mean decline of  $9.9 \mu\text{g/dL}$  (95% CI: 8.7 to 11.2). VNA clients had a mean decline of  $8.3 \mu\text{g/dL}$  (95% CI: 6.1 to 10.5).

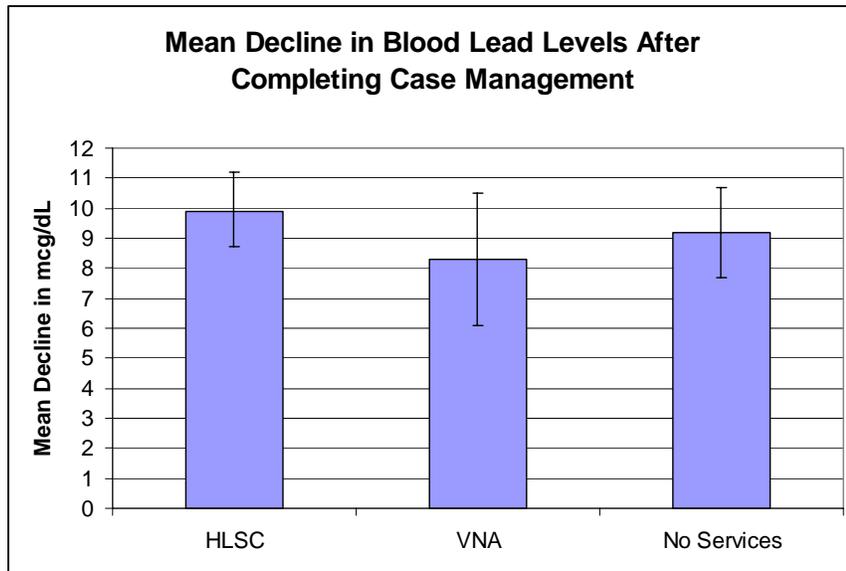
To get a better understanding of the significance of this, we compared these results to those obtained from families who did not complete case management services. Taking the first test after closing the case might bias the results (refusals are expected to close sooner than real cases, and thus have less time between the EBL and the test). Therefore, we instead want to take the test which best approximates the same time window as that from the cases which completed case management. Since the median number of days after the EBL for the case management group was 237, we selected the test for the non-complete group that was after the initial EBL that generated the referral and was closest (in terms of absolute value) to being 237 days after the EBL result. The resulting 245 test results were a median 237 days and mean 270 days after the EBL.

Looking at the declines in this comparison group, 14 of the 245 (5.7%) had no change in BLL ( $\pm 1 \mu\text{g/dL}$ ). 16 of the 245 (6.5%) had an increase in BLL, and the remaining 215 (87.8%) had a decline. The mean decline was 9.8 (95% CI: 8.7 to 10.8), with a median of  $10 \mu\text{g/dL}$ . Since this was amazingly similar to those who completed services, we further broke this down by those who refused the services without receiving any case management (as opposed to receiving some and then dropping out).

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<sup>16</sup> CI – Confidence Interval

Looking at 105 cases where no services were provided, the mean decline was 9.2 (95% CI: 7.7 to 10.7), still with a median of 10  $\mu\text{g}/\text{dL}$ .



There is not a statistically significant difference between the decline observed amongst those receiving complete case management and those receiving partial or no case management ( $p=.65$ ). Nor is there a statistically significant difference in the decline between those receiving full case management and those who refuse services without receiving any case management ( $p=.81$ ). The mean initial EBL levels between those that completed all services ( $25.7 \mu\text{g}/\text{dL}$ ) and those that did not ( $24.8 \mu\text{g}/\text{dL}$ ) was similar and not statistically different ( $p=.16$ ). However, this analysis ignores any number of other potential cofounders that could significantly impact applying this conclusion to a different population. For example, families that refuse services may have more resources or be better able to address the problem than those who accept services, or there may be environmental differences that make the problems more simple or complex. Again, this analysis is not capable of truly determining the relative effectiveness of the interventions applied to a larger population. It only meaningfully demonstrates the outcomes amongst the particular families studied.

### Prevention of Further Poisoning of Those with BLLs of 15 to 19

Between 1999 and 2001, there were 857 children with an incident venous blood test between 15 and 19  $\mu\text{g}/\text{dL}$ . Of those, 723 had another venous test. 514 of those 723 were below 15 on the test immediately following the first test. Thus 71% of incident 15 to 19s went below 15 by the next test.

#### Repoisoning Amongst Significantly Lead Poisoned Children

In total, 38 of the children who completed case management of the 288 with a blood test afterwards (13.1%) at some point had a BLL that was more than  $1 \mu\text{g}/\text{dL}$  greater than their initial blood lead level which triggered case management. Twenty one of them were HLSC clients (out of 192 = 10.9%) and the other 17 were VNA clients (out of 96 = 17.7%). Amongst those who did not complete case management, 31 (of 245 = 12.6%) had a blood test after case closure that was more than a point higher than their initial level.

### **Family Mobility and Continued Lead Safety**

Rhode Island's definition of "lead-safe" requires that lead paint be made intact and non-frictional. It does not require the complete removal of lead. As a result, a structure issued a "lead-safe" certificate can rapidly become dangerous without continuing maintenance. Children living in a well-maintained lead-safe home can still become poisoned from other places they visit or from exotic sources of lead such as a parent's contaminated work clothes. For these reasons, it's important that parents remain vigilant about lead dangers even after their child's blood lead level drops or their dwelling is abated. The importance of continued awareness of lead safety should be an element of the education provided by the case managers.

Unfortunately, data available from administrative records and the parental survey is very limited for evaluating the long-term impact and awareness. Previous sections cover follow-up blood tests and to an extent what content parents remember from the case management and what they are still doing. To further understand whether or not parents continue to apply what they have learned from case management to other situations, we asked parents who have moved if they sought an apartment with fewer lead hazards. In addition, to help understand family mobility, we also asked in a related question, to what extent the lead problems encouraged the families to move.

### **Family Mobility Following Poisoning**

Amongst the families who received case management services, 28% reported moving since learning of their child's lead poisoning. Approximately 40% of those who refused case management services have moved, although the small numbers make it difficult to discern a difference. Amongst both groups, all but two individuals have reported only moving once since learning of the poisoning. In both groups, there was a mixture of about half of those who cited the lead poisoning as a factor in the move and half who said the move was unrelated. Three parents reported being evicted, and associated eviction with difficulties arising from the lead poisoning. Two other parents reported ongoing difficulties with their landlords, and that the lead poisoning was the "last straw" that encouraged them to move. Others mentioned that they were looking for a bigger apartment, moving back in with family, buying their own home, or generally planned on moving anyway, regardless of the lead poisoning.

### **Application of Lead Knowledge to Future Housing Choices**

Those parents who did move were asked whether they attempted to look for a place with fewer lead hazards and if so, did they succeed. By and large, parents attempted to find less hazardous places, although three parents who received case management services indicated that they did not look for a place with fewer hazards. All but one parent who looked for a better place reported finding a place with few hazards. All of the parents who received case management for a significantly poisoned child reported that they believed they could identify potential hazards in their new apartment. One parent who received preventive visits, wasn't sure, and one who refused case management services answered that they could not identify potential hazards.

When asked what they have done to address potential hazards in the new apartment, however, most parents who received case management services responded that their new apartment was lead safe and that there were no hazards. If true, this is a very good thing, although it is likely that better diligence even in "lead safe" environments should be encouraged. Some parents responded that they undertook environmental and cleaning controls, one even mentioning encapsulating a damaged area. All but one

parent who has not received case management services believed there to be no hazards in their new apartment, again suggesting a likely over-estimation of safety.

### **Direct Assistance From Case Manager in Locating Safer Housing**

The parents who did move did not find their case managers to be particularly helpful in locating a new apartment. While several noted that they moved after terminating case management and one noted they never asked the case manager for assistance, none rated their case manager as “very helpful.” One respondent rated the case manager as “somewhat helpful” and the remaining five found their case manager to be “not at all helpful.” Finding ways for case managers to better assist families in locating housing should be further explored.

### **Child and Environment Status at Case Closure**

As was discussed in the Case Closure section of the Process chapter, there are a wide variety of standards for determining when a case manager should close a case as completed. The current “standards” for the HELP Lead Safe Center and for the VNA, as well as the benchmarks recommended by the CDC appear in that section. The Process section on case closure looked at the qualitative reasons for case closure and the perception of the adequacy of the number of services. This section, will cover the quantitative measurements of whether or not abatement was completed, whether the blood lead level was below certain thresholds, and the length of time the case was open prior to being closed.

### **Cases Closed Following Completion of Environmental Enforcement**

While its not required by any policy in RI, a recommendation from the national authorities is that cases be closed from case management only after the environmental hazards have been completely abated. To determine our present success at meeting that criterion, we examined cases where the environmental case was closed with prior to the closure of the case management case. In total, only 17 of the 304 cases (5.6%) that completed case management and had matching inspection records were lead safe prior to the close of the case. Three of those cases had no hazards identified at initial inspection. 14 of the cases were HLSC clients (6.6% of the HLSC cases), and 4 of the cases were VNA clients (1.9% of the VNA cases). Note, however, that this measure is biased by the fact that it is looking at the environmental case where the client lived at the time of the first inspection. It is possible that a substantial number of clients moved prior to the close of the case and the new address was abated prior to the close of case management. Additionally, 24 of the 304 cases (7.9%) had the environmental case closed without completing abatement prior to the end of case management because the parent or relative was the owner of the property. HEALTH assists parent owners in achieving compliance, but does not prosecute parent owners to force compliance.

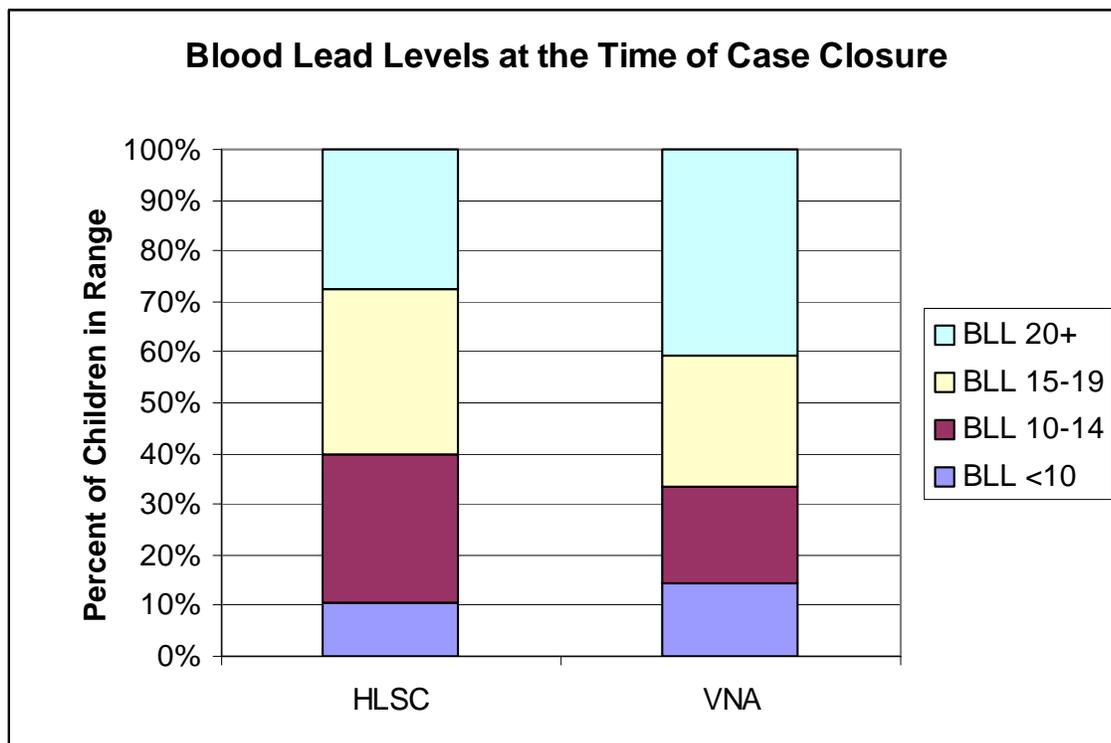
### **Cases Closed Following Decline in BLL to Less Than 20, 15, or 10**

As in the case of abatement, it is a national recommendation (but not part of RI policy) that case management continue until children have a BLL test that reveals they are no longer poisoned. To see how we are doing on that standard, we looked at the final blood lead test prior to the date of closure for the case management test, and only looked at cases who had completed case management services.

Of the 330 children who completed case management and have a valid link to the blood lead tracking, only 255 (77%) had a BLL test during case management. The other 23% would technically violate a standard requiring a drop in BLL to close the case since the test was never performed. For simplicity, however, these cases are excluded from the counts below.

Of the 255 with a blood test while case management was occurring, 29 had a final BLL <10 (11.4%), 99 had a final BLL <15 (38.8%), and 179 had a final BLL <20 (70.2%). The remaining 76 children (29.8%) had a blood lead level at the time of closure exceeding the “significantly” poisoned threshold of >=20. 35 of those children (13.7%) had a blood lead level >= 25. Amongst the 213 clients of HLSC, 23 had a BLL <10 (10.8%), 85 had a BLL <15 (39.9%) and 154 had a BLL <20 (72%). Amongst the 42 clients of the VNA, 6 had a BLL <10 (14.3%), 14 had a BLL <15 (33.3%) and 25 had a BLL < 20 (59.5%).

A total of 25 children had a blood lead level at the time of case closure that was higher than at the time case management was initiated. Twenty-three of these children’s final blood lead levels were above 20. Of the 25 children, 22 were clients of HLSC, and three were clients of the VNA.



**Cases Remaining Open Following Decline**

We looked for cases which had a venous blood lead level below 10 during case management, and counted up the number of days from the day which the result was reported to HEALTH to the day that case was reported as being closed. There were 38 cases that were open for more than 30 days after the venous test <10. Thirty-six cases belonged to HLSC, the other two were VNA cases. Both the VNA cases were closed as having been completed. Twenty-three of the HLSC cases were closed as being completed (representing 9.0% of the completed HLSC cases with BLLs during case management), twelve were closed because the client was lost to follow-up or asked to stop services, and one was closed as a refusal.

Keep in mind, however, that there might have been other circumstance besides BLL that kept the cases open, such as pending mitigation of lead hazards, concern for siblings, etc.

### **Duration of Cases**

To quantify the time taken to complete cases, HEALTH records were searched for the date the case was referred to the agency and the date the agency reported as being the date that the case was closed. Looking at the 332 cases that were closed as being completed, there was a wide variation in the amount of time it took for the cases to be processed. The mean was 136 days (or about 4 and a half months). The median was a similar 141 days. The lower quartile was about six weeks (41 days) and the upper quartile was well over six months (198 days). Looking at only the lead center cases, which have the most accurate recording of open and closed dates, there was somewhat less variation, although the time open was significantly longer. The mean was 178 days, and the median was very close at 175 days, or just short of six months. The lower quartile was at 136 days and the upper quartile was at 213 days, or about seven months. The VNA cases had substantially shorter time frames. The mean was 58 days, or a little under two months. In a highly skewed distribution, the median was only 19 days, or about three weeks. The lower quartile was only 9 days, with the upper quartile being 56 days.

Most of the lead center cases where the case was closed because the parent requested to stop receiving services or where the family was lost to follow-up were open for considerable lengths of time. (The VNA did not have a significant number coded this way). The mean length of time was 155 days, with a similar median of 153 days, only 22 days fewer than those cases brought to completion. The lower quartile was noticeably lower, at 113 days, and the upper quartile was 185 days.

### **Conclusions and Recommendations**

The conclusions and recommendations presented in this section are only one interpretation of a complex and rapidly changing program. The goal of the evaluation effort was not to provide definitive answers or prescriptive recommendations. The purpose was to instead paint a picture of the current state of case management for childhood lead poisoning in Rhode Island and provide a solid base of information for additional consideration. It is our hope that all of the individuals and organizations involved in case management will carefully consider the findings of this work to develop their own conclusions and ideas for improving the care of lead poisoned children.

This disclaimer notwithstanding, we do believe it is important to summarize our understanding of the results presented in the previous chapters and to provide some suggestions for improving the system.

### **Conclusions**

The most significant finding from the survey of those families enrolled in case management, and most powerful result of the complete evaluation, was the degree to which clients are satisfied with the services provided by their case managers. Asked about their experience with the case managers in several different ways, families overwhelmingly rated their case managers as being caring, useful, and knowledgeable. It was difficult for most parents to come up with any suggestions for how to improve the services they received. This not only speaks volumes about the efforts of case managers to

successfully relate to their clients, but it also provides a solid foundation for any interactions with the families. The case managers have successfully engaged the families they serve, and additional messages should be easily delivered.

On the flip side, however, there remains a large number of families who never receive services from a case manager. In many ways, the failure to reach, for one reason or another, 18% of the families referred is the most troubling finding of the evaluation. While the lack of standards for case capture and the difficulty in finding capture rates for comparable programs makes it difficult to assess our relative success, we believe the absolute value is too high regardless. The reasons for refusing case management are varied and ultimately the family's choice to accept or refuse assistance needs to be respected. However, to the extent that refusals are made without a full understanding of the child's need or that the services being offered are misunderstood, refusals present a challenge for improvement.

With the exception of case capture, the process of case management seems to be running quite smoothly. Overall, case managers are initiating contact with the family promptly upon receipt of the referral, and making home visits available rapidly, at times convenient for the families, and with workers who speak the family's language. Families reported overwhelmingly that they knew how to contact their case manager, got immediate answers to their questions, and were treated with respect and courtesy by their case managers. Nearly all the families found the services offered to be useful. Families perceived support and understanding to be just as useful as information. Few parents provided suggestions for ways to improve case management, although some did mention housing assistance and longer-term follow-up as potential options.

The design of the analysis used in the evaluation was not intended to allow for conclusive comparisons between those children who receive and do not receive case management because confounding variables could not be controlled for. However, several measures of the impact of case management are worth considering, even in an absolute sense. Overall, 96.7% of children receiving case management services had at least one follow-up blood lead after they were identified as poisoned, a percentage higher amongst those receiving than refusing services. While the overall follow-up screening rate is good, there is some room for improvement in the timeliness of follow-up screening. A quarter of children had their next follow-up test more than three months after the elevated test, and only 57% of children with a BLL  $\geq$  25 had a follow-up test within the CDC recommended timeframe of a month. Children who were receiving services from the HELP Lead Safe Center had the most prompt follow-up tests, possibly as a result of HLSC's close association with the St. Joseph's Hospital Lead Clinic. There is also room for improvement in making sure that the siblings of lead poisoned children are screened, with parents reporting that 86% of siblings are current on lead screening. Given the increased risk for siblings of lead poisoned children it is especially essential for these children to be routinely screened. While the case managers can not be directly responsible for having the poisoned child or his/her siblings tested, they can serve as important links between the family and the medical provider to help ensure timely and appropriate medical care.

By and large, parents were clearly learning about lead poisoning prevention from their case managers. Nearly all parents who completed services could recall several (and useful) messages about how to implement interim controls, provide proper nutrition, or otherwise help to prevent lead poisoning. Most parents keyed in on environmental controls, which are the most efficacious methods of preventing lead poisoning. Overall, the parents who had gone through the case management process were better able

to offer specific and detailed strategies for addressing lead hazards than those who refused services, and some who refused services mentioned strategies that could potentially increase leaded dust and be harmful. When asked what strategies they continue to perform, however, a large number of parents responded that they no longer worry about lead, often because they believe their home to now be lead safe. Even under the assumption that they are living in certified lead safe units, "lead safe" is only a temporary condition, unless care is taken to maintain it. Parents, both those who did and did not complete case management services, are placing an over-reliance on the "lead safe" certification and failing to maintain vigilance to prevent future lead exposure.

Looking at the children's blood lead levels following initiation of case management services shows significant declines of nearly 10µg/dL on average, but this decline is indistinguishable from the decline seen in children who refused services in this particular study. Given the lack of controls, however, it is impossible to determine whether or not the lack of difference in the decline is a result of a confounding factor or if case management has minimal impact on blood lead levels. The analysis of blood lead levels also shows that approximately 13% of children who both completed and refused services are being further poisoned, with a higher BLL than they started with at some point after initiation of case management. Ideally, once the blood lead level was found at the action level, action taken by the family, case managers, and inspectors would prevent further exposure and the commensurate increase in blood lead levels.

The evaluation showed a wide variation in the reasons for case closure and status of the child and the environment at the time of case closure. While recent CDC recommendations have suggested some stringent standards for officially closing a case, the policies in RI for completing case management are less specific. For families receiving services from the VNAs, the nurses are generally instructed to close the case after two or three home visits, reflected in the fact that the average VNA case is open for a median of less than three weeks. The Lead Center case managers, on the other hand, are expected to maintain contact with the family for a period of months, and have some qualitative closure criteria, including completion of items on the individualized family care plan. This is reflected in their median case length of just under six months. Despite the large difference in the duration of services offered, parents who received both services overwhelmingly stated they were happy with the number of visits they received, perhaps an artifact of having only one set of experiences to draw upon. It is also unclear whether or not this level of satisfaction with the number of visits received is because over a fifth of parents who started case management did not reach completion according to the case manager. While the survey attempted to understand why parents dropped out from services, there were too few surveyed to get an adequate understanding. From the blood lead and environmental case data, however, that almost all (94%) of cases are closed before the environmental remediation of the home is complete, and nearly 30% of children remain significantly lead poisoned ( $BLL \geq 20$ ) at the time their case is closed.

### **Recommendations**

The following recommendations are based upon the findings of this evaluation and upon review of the literature, including the recent CDC recommendations for case management. While HEALTH will continue to play a key role in the case management for lead poisoned children and is well suited for continued evaluation activities, fully considering and implementing these recommendations will require assistance from the Department of Human Services and the Case Management agencies.

- **The case capture rate needs to be improved.** Strategies should be explored that will help to increase the number of families who accept case management services. In cases where the parents can not be located, increased efforts to contact the family through other means should be attempted, including the possibility of keeping their case “pending” for longer time periods to allow for another medical encounter that may then provide new address information for the case manager. In cases where the families are refusing services, it is essential to ensure that families are making an informed decision. To help understand the rationale behind refusals, and to potentially guide future strategies to reach parents, an ongoing evaluation effort should be undertaken to survey or document the reasons for refusals and whether the parents would be interested in alternative services. Similar evaluation measures should be taken amongst parents who drop-out of case management services to help improve the quality of services offered.
- **Case closure criteria should be more explicit, uniform, and incorporate quantitative measurements.** There is currently little uniformity as to the duration of service or to the expectations for the status of the family and child at the time case management services are discontinued. While the January 2<sup>nd</sup>, 2003 opening of three additional Comprehensive Lead Centers and the diminished role for the VNA in lead poisoning may provide a more uniform set of criteria and result in a more uniform duration of service, the criteria will still lack a clear quantitative goal. While implementing the CDC recommendations may be cost prohibitive, setting a measurable blood lead level and environmental goal for case management to reach prior to case closure would help to ensure that families are receiving all the services needed to address the problem.
- **More timely follow-up blood testing, and increased coordination with the child’s PCP is needed.** While the case manager is not directly responsible for ensuring the child receives follow-up blood tests, the case manager should be working with the child’s medical provider and family to ensure these tests are conducted promptly. The three-month follow-up in particular needs to be met, and HEALTH needs to consider whether or not to issue guidance to follow the CDC’s one-month standard for BLLS  $\geq 25$ . Efforts to work more closely with doctors on lead testing also need to include messages on the importance for continued developmental assessment for the child long after his or her blood lead level has declined. The close connection between the HELP Lead Safe Center and the St. Joseph’s Hospital Lead Clinic could also serve as a potential model for coordination between medical care and case management.
- **Educational efforts should include more information on the maintenance of a lead safe environment and long-term vigilance for lead hazards.** While parents by and large are remembering and claim to be following the case managers advise for interim control strategies, they seem to have an inflated sense of the safety of a “lead-safe” house. Educational efforts need to include the message that while lead-safe units are safe at the time of certification, continual attention and diligence is required to keep them lead safe. The importance of ongoing cleaning and other prevention activities should be further stressed. Additionally, developing a term more intuitively descriptive of the actual meaning than “lead-safe” may be useful in helping parents to understand the need for continued vigilance.
- **Strategies to increase compliance with the environmental inspection should be developed.** The refusal rate for environmental inspections amongst those that both accept and refuse case management services is too high and has been steadily increasing in the last few

years. Efforts to better understand and address the concerns that cause parents to refuse the inspection are needed. Helping clients to better understand their legal options and exercise their legal rights may be one way case managers can assist in increasing acceptance of inspection if fear of eviction is a reason. If tenants are behind in the rent, determining if it is possible for inspections to occur after the rent is caught up may also help to alleviate fear and protect the tenant's rights.

- **Improved tracking of referrals to other agencies for assistance should be developed.** While case managers are documenting their efforts to assist the family with non-lead issues by noting referrals to other agencies for assistance, there are currently few mechanisms for seeing that these referrals were acted upon. Developing mechanisms to track referral utilization would help ensure families actually receive needed services. Coordinating with WIC would be an obvious starting point since a lead poisoned child on Medicaid is automatically WIC eligible, and WIC enrollment data is available in HEALTH.
- **Additional research is needed to evaluate the declines in blood lead level resulting from case management.** The lack of a difference in blood lead level decline between those who completed and those who refused case management, while potentially explainable by confounding factors, is a result worthy of further consideration. HEALTH should undertake a more rigorous evaluation of the quantitative outcomes of case management through a randomized or well-controlled study. While inclusion of a "no-service" group may be ethically unacceptable, a study comparing different interventions or the interventions provided by different agencies may still yield useful information about the efficacy of certain approaches and help determine how we can best help families to protect their children.

## References

Centers for Disease Control and Prevention. *Managing Elevated Blood Lead Levels Among Young Children: Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention*. Atlanta: CDC; 2002.

Rhode Island Department of Health. *Family Outreach Home Visiting Program: Request for Proposals*. April 1, 2001.

Rhode Island Department of Human Services. *Specifications for Comprehensive Lead Centers*. July 3, 1998.

## Appendix I – English Version of Parental Survey

Child's name: \_\_\_\_\_

Child ID Code: \_\_\_\_\_

Phone number (actual): \_\_\_\_\_

Date/Time: \_\_\_\_\_

### **Section I: Introduction (EVERYONE)**

(After getting contact – usually mom): Hello. My name is \_\_\_\_\_, and I'm calling from the lead poisoning prevention program at the Rhode Island Department of Health. We are contacting families who were offered services from the Lead Center or a visiting nurse to ask a few questions. Is now a good time to talk with you?

If no, prompt for time to call back: \_\_\_\_\_

If yes, continue:

Your participation will help us improve services for other families. All information you provide us is confidential, and the lead center or nurses will not have access to your responses. If you prefer not to participate, it will not affect any services you receive. If you are uncomfortable answering any particular question you may skip it and continue with the rest of the questions. Would you like to participate?

If no, thank for time and end as refusal.

If yes, continue:

We understand that your (son/daughter) \_\_\_\_\_ (first name) had a high lead level test in \_\_\_\_ (month and year). The \_\_\_\_\_ (lead center or visiting nurse agency) offered to visit you shortly after. We are interested in hearing your thoughts on the services offered by (the lead center or visiting nurse agency) and if you have received services from other agencies or for other children, please tell us what you think only about \_\_\_\_\_ (child's name) visits from \_\_\_\_\_ (lead center or visiting nurse).. If you do not understand what I'm asking, please tell me.

1. **Approximately how long after you learned about the high lead level did the (lead center or VNA) contact you to schedule an appointment to visit?**
  - A. Same day
  - B. Within 3 days
  - C. Within a week
  - D. Within two weeks
  - E. Less than a month
  - F. More than a month
  
2. **Did you receive at least one visit from the lead center or visiting nurse agency, or did you choose not to receive any services from them?**
  - A. Received at least one visit
  - B. Refused Services (skip to Section III)

*Section II: Case Management Eval (For those that accepted services ONLY)*

3. How long did you have to wait to get an appointment with a case manager or home visitor?

- A. Less than 3 days
- B. Less than a week
- C. Less than two weeks
- D. Less than a month
- E. More than a month

(Check consistency: add up time from 1 and 3 and ask, **So it was a total of about \_\_\_\_ (time) from when you first learned about the elevated level to when someone came out to your home?** Clarify and correct other responses if necessary.)

4. Thinking of both the first visit and future visits, were the times available:

- A. Convenient
- B. Not convenient; what would be a better time for you?
- C. Earlier in the morning
- D. Later in the evening
- E. On a Saturday
- F. On a Sunday

5. Did you have problems communicating with the home visitor or case manager because of language?

- A. Yes (Prompt for more information: What language is their primary one\_\_\_\_\_, Did the lead educator not speak this language? Spoke it poorly?)
- B. No

6. Did you know how to get in contact with your home visitor or case manager if you needed to?

- A. Yes
- B. No

7. When you called the lead center or the visiting nurse agency with questions or to make appointments, in general, were your questions answered:

- A. Immediately when you called
- B. When someone called you back the same or the next day
- C. When someone called you back two or more days later
- D. Only after you called multiple times
- E. Your questions were never answered
- F. You never called the lead center or visiting nurse agency

8. Has \_\_\_\_\_ been hospitalized because of this lead level?

- A. Yes
- B. No (If no go to Question 11)

9. Did a case manager or home visitor contact you while \_\_\_\_\_ was in the hospital?

- A. Yes
- B. No

10. Did the home visitor or case manager help you make your home lead safe or help you find a lead safe home before your child was discharged from the hospital?

- A. Yes
- B. No

11. Did the home visitor or case manager discuss with you how frequently your child's blood should be tested for lead?

- A. Yes
- B. No

12. How easy was it for you to have your child tested for lead?

- A. Very easy
- B. Somewhat easy
- C. Somewhat difficult
- D. Very difficult

If somewhat or very difficult, prompt: **Why was it difficult, and what would have made it easier?**

13. In general, how much do you believe parents can prevent lead poisoning in their children?

- A. Parents can completely prevent lead poisoning
- B. Parents can somewhat prevent lead poisoning
- C. Parents cannot do much to prevent lead poisoning
- D. There is nothing parents can do to prevent lead poisoning

14. Did the case manager or nurse discuss with you how to protect your child? If Yes, how? (Free response.... If absolutely necessary prompt them on cleaning, nutrition. Once they offer something, get specifics – i.e. if they say cleaning, find out how (especially if it was sweeping vs. vacuuming vs. wet mopping) and how often – if they say nutrition or vitamins, try to find out how much and how frequent. Also if possible, try to get a sense of which were new concepts because of the nurse, and which may have been things they already did.)

15. Which of the steps you just mentioned are you STILL doing?

16. In general, how courteous and respectful were the case managers or home visitors when they came to your home?

- A. Very courteous and respectful
- B. Somewhat courteous and respectful
- C. Somewhat discourteous and disrespectful
- D. Very discourteous and disrespectful

17. Overall, how useful was the case manager or home visitor in helping you to protect your child?

- A. Very useful
- B. Somewhat useful
- C. Somewhat useless
- D. Not at all useful

18. What did the case manager or home visitor do that was particularly helpful for you?

19. What did the case manager or home visitor do that was not helpful for you or you felt was a waste of time?

20. **Are there any services that you would have liked to receive and didn't, or is there anything more that the home visitor or case manager could have done to help you?**

21. **When you stop receiving services from the home visitor or case manager, was it because?**

- A. You requested to stop receiving services (ask 22)
- B. The Lead Center/VNA discharged you (Skip to 23)
- C. Both you and the Lead Center/VNA agreed to stop the services (Skip to 23)

(Note: if necessary, have them explain the situation and choose the appropriate response – the “normal” situation is for the nurse/case manager to close the case – option B – so if it was a mutual decision, then B is the response.)

22. **Why did you ask to stop getting the services? (free response)**

23. **Thinking about the number of visits you received from the home visitor or case manager, would you say that:**

- A. Fewer visits would have been better
- B. Number of visits received was good
- C. More visits would have been better

NOTE: IF INTERVIEWING PARENT THAT WENT THROUGH FOP SINGLE 15PREVENTIVE VISIT, SKIP TO 29)

24. **In addition to the services from a home visitor or case manager, you were offered a free inspection for lead hazards in your home? In scheduling the home inspector:**

- A. Did the home visitor or case manager help you arrange a time for the inspector to come to your home, (Skip to 26)
- B. Did you schedule a time for the inspector to come (skip to 26)
- C. Did you ask the inspector not to come?
- D. You do not remember being offered an inspection(skip to 29)

25. **Please tell me why you asked the inspector not to come?**

(Free response question – if possible quote verbatim with quotation marks – if not possible please summarize)

(Skip to Q 29)

26. **Was the inspector available to come to your home at a time that was convenient for you?**

- A. Times available were very convenient for you
- B. Time available were somewhat convenient for you
- C. Times available were somewhat not convenient for you
- D. Time available were not convenient for you

27. **After the inspection, how long did it take before you received the results of the inspection?**

- A. Within a week
- B. Within two weeks
- C. Less than a month
- D. Over a month
- E. Never Received the Inspection results

28. Did the case manager or home visitor help you to understand the inspection results?  
A. Yes  
B. No
29. Since you found out about your child's high lead level, have you moved to a new house or apartment?  
A. Yes... How many times did you move: \_\_\_\_\_  
B. No (Skip section IV)
30. Did your move(s) have anything to do with your child's lead level? If so, please describe.  
(free response – did they move to try to find a safer apartment? Because of the "trouble" were they forced to move by their landlord? Describe the circumstances.)
31. When you moved, did you try to find an apartment with fewer lead hazards and if so, did you succeed?  
A. Yes, looked, but could not find apartment with fewer lead hazards  
B. Yes, looked for and found apartment with fewer lead hazards  
C. No, did not look for apartment with fewer lead hazards
32. How helpful was your case manager or home visitor in helping you find a new apartment?  
Had already stopped working with the home visitor or case manager by the time I moved  
A. Very helpful  
B. Somewhat helpful  
C. Not at all helpful
33. Do you feel that you can identify potential lead hazards in your new apartment?  
A. Yes  
B. No
34. Have you done anything to address lead hazards in your new apartment? If so, what?  
(free response)

SKIP TO SECTION IV

*Section III: Refusal info and Housing Info (For Those That REFUSED Case Management ONLY)*

35. Can you please tell me why you chose not to accept services from the nurse agency or lead center?
36. Are there alternative services you would have liked to receive had they been offered?
37. **(12R) How easy was it for you to have your child tested for lead?**  
A. Very easy  
B. Somewhat easy  
C. Somewhat difficult  
D. Very difficult  
If somewhat or very difficult, prompt: **Why was it difficult, and what would have made it easier?**
38. **(13R) In general, how much do you believe parents can prevent lead poisoning in their children?**  
A. Parents can completely prevent lead poisoning  
B. Parents can somewhat prevent lead poisoning  
C. Parents can not do much to prevent lead poisoning  
D. There is nothing parents can do to prevent lead poisoning
39. **(14R) While your child had a high lead level; did you take any actions to help protect your child? If yes, how?** (Free response.... If absolutely necessary prompt them on cleaning, nutrition. Once they offer something, get specifics – i.e. if they say cleaning, find out how (especially if it was sweeping vs. vacuuming vs. wet mopping) and how often – if they say nutrition or vitamins, try to find out how much and how frequent. Also if possible, try to get a sense of which were new concepts because of the nurse, and which may have been things they already did.)
40. **(15R) which of the items you just mentioned are you STILL doing?**

NOTE: IF INTERVIEWING PARENT THAT WENT THROUGH FOP SINGLE 15PREVENTIVE VISIT, SKIP TO 45

41. **(24R) In addition to the services from a home visitor or case manager, you were offered a free inspection for lead hazards in your home?**  
A. Did you schedule a time for the inspector to come (skip to 43)  
B. Did you ask the inspector not to come?  
C. You do not remember being offered an inspection
42. **(If accepted inspection, skip to 43) (25R) Please tell me why you asked the inspector not to come?** (Free response question – if possible quote verbatim with quotation marks – if not possible please summarize) (Skip to 45)
43. **(26R) Was the inspector available to come to your home at a time that was convenient for you?**  
A. Times available were very convenient for you  
B. Time available were somewhat convenient for you  
C. Times available were somewhat not convenient for you  
D. Time available were not convenient for you

44. (27R) After the inspection, how long did it take before you received the results of the inspection?
- A. Within a week
  - B. Within two weeks
  - C. Less than a month
  - D. Over a month
  - E. Never Received the Inspection results
45. (29R) Since you found out about your child's high lead level, have you moved to a new house or apartment?
- A. Yes... How many times did you move: \_\_\_\_\_
  - B. No (Skip to Section IV)
46. (30R) Did your move(s) have anything to do with your child's lead level? If so, please describe. (free response – did they move to try to find a safer apartment? Because of the "trouble" were they forced to move by their landlord? Describe the circumstances.)
47. (31R) When you moved, did you try to find an apartment with fewer lead hazards and if so, did you succeed?
- A. Yes, looked, but could not find apartment with fewer lead hazards
  - B. Yes, looked for and found apartment with fewer lead hazards
  - C. No, did not look for apartment with fewer lead hazards
48. (33R) Do you feel that you can identify potential lead hazards in your new apartment?
- A. Yes
  - B. No
49. (34R) Have you done anything to address lead hazards in your new apartment? If so, what? (free response)

*Section IV: General Info: FOR EVERYONE*

50. Besides \_\_\_\_\_ (child first name), are there any other children under the age of 6 who reside in your household?
- A. No
  - B. Yes; If so, approximately when was the last time they were screened for lead?
    - 1. too young to have been screened (<9 months old)
    - 2. screened in last 3 months
    - 3. screened in last 6 months
    - 4. screened in last year
    - 5. screened over a year ago
    - 6. never have been screened
    - 7. not sure when last screened
51. At the time your child had the high lead level, did you rent or own your apartment or house, or did you live with family or friends who pay the rent or own ?
- A. Rent
  - B. Own (Skip to 54)
  - C. Live with family/friends (skip to 54)
52. BEFORE your child tested high for lead, how would you describe your relationship with your landlord?
- A. Excellent
  - B. Good
  - C. Fair
  - D. Poor
53. AFTER your landlord was informed your child tested high for lead, how would you describe your relationship with your landlord?
- A. Excellent
  - B. Good
  - C. Fair
  - D. Poor
54. How many times have you moved in the last three years? During the next three years, do you plan on:
- A. Staying in your current home or apartment
  - B. Moving to a different home or apartment in the same neighborhood
  - C. Moving to a different neighborhood in the same city
  - D. Moving to a different city
55. In the future we may be conducting focus groups, or group discussions, on case management. Participants would be paid for their time. Is it ok for us to call again in the future to invite you to such a group?
- A. Yes
  - B. No

Thank you very much for your participation in this survey. We appreciate your time, and your responses will help us improve the services offered to families in the future. Should you have any concerns about this survey, please feel free to call Patrick MacRoy, our Epidemiologist, at 222-7730. Have a good afternoon.

## Appendix II – Spanish Version of Parental Survey

Nombre del niño: \_\_\_\_\_

Child ID: \_\_\_\_\_

Número de teléfono actual: \_\_\_\_\_

Fecha/hora: \_\_\_\_\_

### Sección I: Introducción (TODOS)

**(Después de haber contactado normalmente a la mamá):** Hola. Mi nombre es \_\_\_\_\_, Le estoy llamando del Departamento de Salud del Programa de Plomo, Estamos llamando a las familias que se les ofreció los servicios del Centro del Plomo (Lead Center) o de las Enfermeras a Domicilio (Visiting Nurses). ¿Es ahora buen tiempo para hablar con usted?

Si dicen que no, pregunte a que hora se puede volver a llamar \_\_\_\_\_ am pm

Si dicen que si, continúe:

Su participación nos ayudara a mejorar los servicios para otras familias. La información que usted me de es confidencial, ni el Centro del Plomo ni las Enfermeras a Domicilio tendran acceso a sus respuestas. Si prefiere no participar, eso no le afectara los servicios que recibe. Si hay alguna pregunta que prefiere no contestar, me dice y pasamos a la siguiente.

Si dicen que no, agradezca por el tiempo que le ofrecieron y marque esta entrevista como "Refusal".

Si dicen que si, continúe:

Entendemos que su (hijo/hija) \_\_\_\_\_ (nombre) tuvo un alto nivel de plomo en (mes/año) \_\_\_\_\_. El Centro de Plomo o las Enfermeras a Domicilio le ofrecio una visita poco después de recibir los resultados del examen de plomo. Nos interesa saber lo que piensa de los servicios que le ofrecio el Centro del Plomo o la Agencia de Enfermeras a Domicilio. Si recibió servicios de otras agencias o para otro de sus hijos, por favor sólo dígame lo que piensa sobre las visitas de \_\_\_\_\_ (nombre de niño). Podemos comenzar?

1. **Aproximadamente cuanto tiempo después que se enteró que su hijo tenía plomo recibió una llamada del (Centro del Plomo o Enfermeras a Domicilio) para hacer una cita y visitarle en su casa?**
  - A. El mismo día
  - B. Dentro de 3 días
  - C. Dentro de una semana
  - D. Dentro de dos semanas
  - E. Menos de un mes
  - F. Más de un mes
  
2. **Recibió por lo menos UNA visita del Centro de Plomo o las Enfermeras Visitantes, o decidió no recibir ningún servicio?**
  - A. Recibió por lo menos una visita
  - B. Se negó a recibir los servicios de la agencia (vaya a la Sección III)

Sección II: Evaluación del manejo de casos (SOLO para aquellos que aceptaron los servicios)

3. ¿Cuánto tiempo espero antes que le dieran una cita con el visitante (no el inspector)?

- A. Menos de 3 días
- B. Menos de una semana
- C. Menos de dos semanas
- D. Menos de un mes

(Verifique: sume el tiempo de las respuestas 1 y 3 y pregunte: ¿Entonces fue un total de \_\_\_\_ (tiempo) desde que usted supo que su niño tenía plomo hasta que alguien fue a visitarle en su casa? Aclare las respuestas y corrija de ser necesario.)

4. Pensando en la primera visita y las siguientes visitas, cree que:

- A. Las horas de visita eran convenientes.
- B. Las horas de visita no eran convenientes; ¿Qué hora hubiera sido mejor para visitarle?
- C. Más temprano en la mañana
- D. Más tarde en la noche
- E. Un sábado
- F. Un domingo

5. ¿Tuvo problemas para comunicarse con el visitante debido al idioma?

- A. Si (Pregunte: Cual es el idioma que hablan en la casa \_\_\_\_\_, la persona que vino a visitarle no hablaba ese idioma? O hablaba muy poco el idioma?)
- B. No

6. ¿Sabía usted como contactar el visitante en caso de necesitarlo?

- A. Si
- B. No

7. Cuando usted llamó al Centro de Plomo o las Enfermeras a Domicilio con preguntas o para hacer una cita, como le respondieron:

- A. Inmediatamente cuando usted llamó
- B. Alguien llamó a su casa el mismo día o el día siguiente
- C. Alguien llamó a su casa dos días después
- D. Solo después que usted llamó varias veces
- E. Nunca le contestaron sus preguntas
- F. Usted nunca llamó al Centro de Plomo o las Enfermeras a Domicilio

8. Estuvo \_\_\_\_\_ en hospital por este nivel alto de plomo

- A. Si
- B. No ( Vaya a pregunta 11)

9. ¿Le llamó o contactó de alguna forma el visitante mientras \_\_\_\_\_ estaba en el hospital?

- A. Si
- B. No

10. ¿Le ayudó el visitante a hacer su casa más segura para el plomo o le ayudó a encontrar un lugar sin plomo para llevar al niño cuando salió del hospital?

- A. Si
- B. No

11. ¿ Le informo el visitante acerca de la frecuencia con que debe ser examinada la sangre de su hijo para detectar el plomo?

- A. Si
- B. No

12. ¿Que tan fácil fue hacerle a su niño el examen del plomo?
- A. Muy fácil
  - B. Algo fácil
  - C. Algo difícil
  - D. Muy difícil

Si fue un poco o muy difícil, pregunte: ¿Porqué fue difícil, y que es lo que le hubiera hecho más fácil?

13. En general, cree usted que:
- A. Los padres pueden prevenir COMPLETAMENTE el envenenamiento con plomo
  - B. Los padres pueden en ALGO prevenir el envenenamiento con plomo
  - C. Los padres NO PUEDEN HACER MUCHO para prevenir el envenenamiento con plomo
  - D. NO HAY NADA que los padres puedan hacer para prevenir el envenenamiento con plomo
14. ¿Habló con usted el visitante sobre como puede proteger a su niño del envenenamiento de plomo? Qué pasos le recomendaron? (Free response.... If absolutely necessary prompt them on cleaning, nutrition. Once they offer something, get specifics – i.e. if they say cleaning, find out how (especially if it was sweeping vs. vacuuming vs. wet mopping) and how often – if they say nutrition or vitamins, try to find out how much and how frequent. Also if possible, try to get a sense of which were new concepts because of the nurse, and which may have been things they already did.)
15. ¿De los pasos que le mencionó el visitante, cuales hace TODAVÍA?
16. En general, que tan cortés y respetuoso era el visitante:
- A. Muy cortés y respetuoso
  - B. Un poco cortés y respetuoso
  - C. Un poco descortés y no muy respetuoso
  - D. Muy descortés y no respetuosos
17. En resumen, ¿que tan útil fue el visitante para ayudarle a proteger a su niño:
- A. Muy útil
  - B. Algo útil
  - C. Algo inútil
  - D. Muy inútil
18. ¿El visitante hizo algo que fue particularmente útil para usted?
19. ¿El visitante hizo algo que no fue útil para usted o le hizo pensar que era una pérdida de tiempo?
20. ¿Hubo algún servicio que usted no recibió y le hubiera gustado recibir, o hay algo más que el visitante pudo hacer para ayudarle más?

21. ¿Cuándo termino de recibir los servicios de el visitante, fue porque:  
 A. Usted pidio que pararan los servicios.(pregunte 22)  
 B. El Centro de Plomo o las Enfermeras Visitantes cerraron el caso (Vaya a la pregunta 23)  
 (Note: if necessary, have them explain the situation and choose the appropriate response – the “normal” situation is for the nurse/case manager to close the case – option B – so if it was a mutual decision, then B is the response.)
22. ¿Porque pidio no recibir más servicios? (free response)
23. Pensando en el número de visitas que recibió, usted diría que:  
 A. Hubiera sido mejor MENOS visitas  
 B. El número de visitas estuvo bien  
 C. MÁS visitas hubieran sido mejor

NOTE: IF INTEVIEWING PARENT THAT WENT THROUGH FOP SINGLE 15PREVENTIVE VISIT, SKIP TO 29

24. Además de los servicios del visitante, le ofrecieron una inspección para detectar plomo en su casa sin costo alguno? Para hacer la cita con el inspector:  
 A. Le ayudo el visitante o administrador de casos a fijar la cita (pregunta 26)  
 B. Usted hizo la cita sin ayuda de nadie (vaya a la pregunta 26)  
 C. Usted se nego a recibir la inspeccion?  
 D. No se acuerda que le ofrecieron una inspección
25. (Si aceptó la inspección, vaya a la pregunta 26) Nos podría decir ¿porque se negó a recibir la inspección?  
 (Free response question – if possible quote verbatim with quotation marks – if not possible please summarize) (Skip to Q 29)
26. ¿Las horas que el inspector estaba disponible para ir a su casa eran:  
 A. convenientes  
 B. algo convenientes  
 C. algo inconvenientes  
 D. no era convenientes
27. En cuánto tiempo recibio los resultados de la inspección:  
 A. Dentro de una semana  
 B. Dentro de dos semanas  
 C. Menos de un mes  
 D. Más de un mes  
 E. Nunca recibí los resultados de la inspección
28. ¿El visitante le ayudó a entender los resultados de la inspección?  
 A. Si  
 B. No
29. ¿Se mudo a una nueva casa o apartamento cuando supo que su niño tenía un alto nivel de plomo,?  
 A. Si... Cuantas veces se ha mudado: \_\_\_\_\_  
 B. No (vaya a seccion IV)
30. ¿Su mudanza tuvo algo que ver con el nivel del plomo de su niño? Si es así, por favor cuéntenos un poco más al respecto. (free response – did they move to try to find a safer apartment? Because of the “trouble” were they forced to move by their landlord? Describe the circumstances.)

31. Cuando se mudó, trató de encontrar un apartamento con menos peligros de plomo?  
A. Si, busqué, pero no pude encontrar un apartamento con menos plomo  
B. Si busqué y encontré un apartamento con menos plomo  
C. No busqué un apartamento con menos plomo
32. ¿Que tanto le ayudo el visitante para encontrar un nuevo apartamento?  
A. Ayudó mucho  
B. Ayudó algo  
C. No No le ayudo en nada  
D. Ya no estaba en contacto con el visitante
33. ¿Usted piensa que puede identificar los peligros del plomo en su nuevo apartamento?  
A. Si  
B. No
34. ¿Ha hecho algo para remediar los posibles peligros de plomo en su nuevo apartamento?  
A. Si.....Qué ha hecho? (free response  
B. No)

VAYA A LA SECCION IV

Sección III: Información acerca de los casos en que se negó a recibir los servicios y acerca de la vivienda (SOLO para los que se NEGARON a recibir los servicios)

35. ¿Me podría decir porque no aceptó los servicios del Centro del Plomo o Enfermeras a Domicilio?
36. Hay otros servicios alternativos que le hubiera gustado recibir si se le hubieran ofrecido?
37. (12R) ¿Que tan fácil fue hacerle a su niño el examen del plomo?  
A. Muy fácil  
B. Algo fácil  
C. Algo difícil  
D. Muy difícil

Si contestó algo o muy difícil, pregunte: **Porque fue difícil, que lo hubiera hecho fácil?**

38. (13R) En general, cree usted que:  
A. Los padres pueden prevenir COMPLETAMENTE el envenenamiento con plomo  
B. Los padres pueden en ALGO prevenir el envenenamiento con plomo  
C. Los padres NO PUEDEN HACER MUCHO para prevenir el envenenamiento con plomo  
D. NO HAY NADA que los padres puedan hacer para prevenir el envenenamiento con plomo
39. (14R) ¿Mientras su niño tenía un alto nivel de plomo, hizo algo para ayudar a proteger a niño? (Free response.... If absolutely necessary prompt them on cleaning, nutrition. Once they offer something, get specifics – i.e. if they say cleaning, find out how (especially if it was sweeping vs. vacuuming vs. wet mopping) and how often – if they say nutrition or vitamins, try to find out how much and how frequent. Also if possible, try to get a sense of concepts, and which may have been things they already did.)
40. (15R) ¿De los pasos que le mencionó el visitante, cuales hace TODAVÍA?

NOTE: IF INTERVIEWING PARENT THAT WENT THROUGH FOP SINGLE 15PREVENTIVE VISIT, SKIP TO 44

41. (24R) Además de los servicios del visitante, le ofrecieron una inspección para detectar plomo en su casa sin costo alguno? Para hacer la cita con el inspector:  
A. Le ayudo el visitante o administrador de casos a fijar la cita (pregunta 43)  
B. Usted hizo la cita sin ayuda de nadie (vaya a la pregunta 43)  
C. Usted se negó a recibir la inspección?  
D. No se acuerda que le ofrecieron una inspección
42. (Si aceptó la inspección, vaya a la pregunta 43) (25R) Nos podría decir ¿porque se negó a recibir la inspección?  
(Free response question – if possible quote verbatim with quotation marks – if not possible please summarize)  
(Skip to 45)
43. (26R) ¿Las horas que el inspector estaba disponible para ir a su casa eran:  
A. conveniente

- B. algo conveniente
- C. algo inconveniente
- D. no eran conveniente

44. (27R) En cuánto tiempo recibí los resultados de la inspección:
- A. Dentro de una semana
  - B. Dentro de dos semanas
  - C. Menos de un mes
  - D. Más de un mes
  - E. Nunca recibí los resultados de la inspección
45. (29R) ¿Se mudó a una nueva casa o apartamento cuando supo que su niño tenía un alto nivel de plomo,?
- A. Si... Cuantas veces se ha mudado: \_\_\_\_\_
  - B. No (vaya a la pregunta 46)
46. (30R) ¿Su mudanza tuvo algo que ver con el nivel del plomo de su niño? Si es así, por favor cuéntenos un poco más al respecto. (free response – did they move to try to find a safer apartment? Because of the “trouble” were they forced to move by their landlord? Describe the circumstances.)
47. (31R) Cuando se mudó, trató de encontrar un apartamento con menos peligros de plomo?
- A. Si, busqué, pero no pude encontrar un apartamento con menos plomo
  - B. Si busqué y encontré un apartamento con menos plomo
  - C. No busqué un apartamento con menos plomo
48. (33R) ¿Usted piensa que puede identificar los peligros del plomo en su nuevo apartamento?
- A. Si
  - B. No
49. (34R) ¿Ha hecho algo para remediar los posibles peligros de plomo en su nuevo apartamento?
- A. Si...Qué ha hecho? (free response)
  - B. No)

#### Sección IV: Información General: PARA TODOS

50. Además de \_\_\_\_\_ (nombre del niño), hay otros niños menores de 6 años en su casa?
- A. No hay otros niños en la casa
  - B. Si los hay, cuando fue la última vez que se hicieron el examen del plomo?
    1. Son muy pequeños para hacerse el examen (<9 meses)
    2. últimos 3 meses
    3. últimos 6 meses
    4. hace un año
    5. hace más de un año
    6. nunca se han hecho el examen de plomo
    7. No saben cuando le hicieron el examen de plomo
51. Cuando su niño tuvo un alto nivel de plomo, usted:
- A. Rentaba
  - B. Tenía Casa propia (vaya a la pregunta 54)
  - C. Vivía con familiares/amigos (vaya a la pregunta 54)

52. Como era su relación con el dueño de casa ANTES que el supo que su niño tenía un nivel alto de plomo,
- A. Excelente
  - B. Buena
  - C. Más o menos
  - D. Mala
53. Como era su relación con el dueño de casa DESPUES que el supo que su niño tenía un nivel alto de plomo,
- A. Excelente
  - B. Buena
  - C. Más o menos
  - D. Mala
54. ¿Cuántas veces se ha mudado en los últimos 3 años?
55. Durante los próximos 3 años, usted piensa:
- A. Quedarse en el mismo apartamento o casa
  - B. Mudarse a una casa diferente o apartamento en el mismo barrio
  - C. Mudarse a un barrio diferente en la misma ciudad
  - D. Mudarse a otra ciudad
56. En el futuro talvez reunemos un grupo de padres de niños que tuvieron un alto nivel de plomo. A los participantes normalmente se les paga por el tiempo. Le podríamos volver a llamar para invitarle a participar en alguno de estos grupos?
- A. Si
  - B. No

Muchas gracias por su participación. Le agradecemos su tiempo, y sus respuestas nos van a ayudar a mejorar los servicios que se ofrecerán a familias como la suya en el futuro. Si usted tiene alguna pregunta acerca de esta encuesta, por favor llame a Magaly Angeloni, Directora del Programa del Plomo, al 222-4602. Que tenga un buen día.

For more information, contact:

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