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Preventing Childhood Lead Poisoning in New Jersey

Advocates and State Government Working Together to Increase the Lead Screening of Children

ACLU
AMERICAN CIVIL LIBERTIES UNION

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An ACLU Report

Preventing Childhood Lead Poisoning in New Jersey:

Advocates and State Government Working Together to Increase the Lead Screening of Children

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Preventing Childhood Lead Poisoning in New Jersey:

Advocates and State Government Working Together to Increase the Lead Screening of Children

I. INTRODUCTION

During the last five years, the number of New Jersey children enrolled in Medicaid who have been tested for childhood lead poisoning has increased significantly. Working together, advocates and New Jersey's Medicaid agency have shown that targeted outreach and education to parents and medical professionals can have a meaningful impact on the identification and treatment of lead poisoned children.

Although childhood lead poisoning has been a major public health issue in New Jersey for many years, public health officials paid it little attention. Of the estimated 18,000 children under the age of six suffering from lead poisoning in 2000, the state's public health agency, the Department of Health and Senior Services (DHSS), had only identified one-third. Slightly less than one-half of those children were enrolled in Medicaid. Hundreds were not receiving necessary follow-up treatment.

The American Civil Liberties Union, the American Civil Liberties Union of New Jersey (collectively, the ACLU), the Association for Children of New Jersey (ACNJ), Legal Services of New Jersey (LSNJ) and, later, the Office of the Child Advocate threatened to bring suit against DHSS and the state's Medicaid agency unless they took immediate steps to improve their lead poisoning prevention efforts. In response to that threat, the state's Medicaid agency invited the ACLU, ACNJ and other advocates to work with it to identify those Medicaid-enrolled children suffering from lead poisoning and to ensure that they received necessary treatment. After five years, this collaboration has resulted in a near doubling in the lead screening rate of Medicaid-enrolled children ages one and two from 25% to 45%, and the development of systems to ensure that lead burdened Medicaid-enrolled children receive corrective treatment. This report describes the strategies employed by the state's Medicaid agency, the ACLU and ACNJ to improve lead poisoning prevention efforts. It further describes the reluctance of the state's public health agency to participate in those efforts and its inability to provide effective leadership in this area.

In October 2004, that agency announced as a goal the elimination of childhood lead poisoning in New Jersey by the year 2010. While ACLU, ACNJ, Legal Services of New Jersey and the Office of the Child Advocate applaud this goal, they call upon DHSS to take an active role in achieving it by working collaboratively with the state's Medicaid agency to institutionalize and expand upon the reform strategies set forth in this report.

II. NEW JERSEY'S CHILDHOOD LEAD POISONING PREVENTION PROGRAM: A SYSTEM IN CRISIS

Once in the body, lead is a powerful toxin. It can cause developmental delays, learning disabilities, behavioral problems, hyperactivity, and in some cases, convulsions, coma and

death.[1] Children six years old and younger are particularly vulnerable to the damaging effects of lead because their central nervous systems are not fully developed and their bodies absorb and retain it to a greater extent than do the bodies of adults.[2]

Although children from all socioeconomic groups can be effected, those from low-income and minority families are at greatest risk. African American children are almost five times as likely as Caucasian children to be lead-burdened. Low-income children are eight times as likely to be lead-burdened as children from wealthier backgrounds.[3] An estimated 60% of all children suffering from childhood lead poisoning are enrolled in Medicaid.[4]

Since at the most common levels of exposure lead poisoning does not present identifiable symptoms, the only way to determine whether a child is lead burdened is with a blood test.[5] In New Jersey, all children under the age of six are legally entitled to such testing. The federal Medicaid Act requires state Medicaid programs to provide Medicaid-enrolled children with a lead blood test at 12 months and again at 24 months (or between 36 and 72 months if the child failed to receive a screen at either 12 or 24 months).[6] New Jersey's Lead Poisoning Abatement and Control Act (more commonly referred to as the "Universal Screening Law"), promulgated in 1996, requires local boards of health to work with medical professionals to provide all New Jersey children, not just those who are Medicaid-eligible, with lead screening pursuant to the same time table set forth in the Medicaid Act.[7]

In 2000, New Jersey's childhood lead poisoning prevention program was far from compliant with these regulations. An estimated 18,600 children under the age of six were thought to be lead burdened,[8] but New Jersey was doing little to locate these children and even less to treat them. State screening[9] rates were so low (during state fiscal year 2000, only 25% of one and two-year olds enrolled in Medicaid[10] and one third of all one and two-year olds received a lead blood test[11]) that as of June 2000, state public health officials had identified only one third of the 18,600 children.[12] Even worse, of that one third, more than one half were not receiving any follow-up services.[13]

The Medicaid Act requires state Medicaid agencies to provide follow-up services to Medicaid-enrolled children with blood lead levels (BLL) over 10 micrograms of lead per deciliter of whole blood (μg/dL) in accordance with guidelines promulgated by the Centers for Disease Control and Prevention (CDC).[14] The CDC recommends that children with persistent blood lead levels (BLLs) of between 15 and 19μg/dL or BLLs over 20μg/dL receive regular and periodic follow-up blood lead tests, case management services[15] and environmental hazard assessments to determine the source of their exposure. It further recommends that environmental assessments be conducted "as soon as possible" after a confirmatory blood test identifying a child as lead burdened.[16]

The state Universal Screening Law mandates that local health departments, under DHSS' supervision, provide follow-up testing, case management services and environmental assessments to the same groups of children identified by the CDC.[17] Because the most common source of exposure for children is deteriorating lead-based paint in older housing,[18] the law also requires local health departments to order the abatement of any home or housing unit determined to contain a lead hazard.[19] If a property owner fails to abate, the local board may arrange for the abatement at

the owner's expense.[20] If the local health department fails to enforce the abatement laws, DHSS may move to enforce them.[21]

In 2000, however, children known to have persistent BLLs of between 15 and 19μg/dL were not receiving any case management services. Moreover, by the end of state fiscal year 2000, local health departments had completed only 60% of the mandated environmental assessments,[22] and landlords and property owners had abated only 22% of the properties with identified lead hazards.[23]

III. INSTITUTIONAL IMPEDIMENTS TO SCREENING AND TREATMENT

Concerned about the state's low screening rates and its failure to provide case management services and environmental hazard assessments, the ACLU, ACNJ, Legal Services of New Jersey, and later, the Office of the Child Advocate, began to interview state and local officials, to attend inter-agency meetings and conferences, and to review documents obtained through New Jersey's Public Records Act to determine why children were not receiving services to which they were legally entitled. Their investigation revealed the following:

A. No leadership

Although DHSS and DMAHS share responsibility for screening and treatment,[24] the Universal Screening Law contemplates that DHSS will exercise a leadership role. Among other things, it requires DHSS to: develop, implement and coordinate "a program to control lead poisoning,"[25] maintain a "central data base which shall include a record of all lead screening conducted pursuant to this Act,"[26] and "conduct a public information campaign" to inform parents and health care providers of the Universal Screening Law's lead screening requirements.[27] As of 2000, four years after the law was passed, DHSS had done none of these things. Although DMAHS theoretically could have stepped forward to fill this void, it had not.

B. No adequate surveillance system

Good data collection is essential to administering any effective lead poisoning prevention program. It enables states to ensure that they are reaching the children at highest risk, to monitor physicians and clinics responsible for providing screening, and to confirm that children who have been lead poisoned are receiving necessary follow-up care.[28] Yet, as of 2000, neither DMAHS nor DHSS had functional surveillance systems tracking lead screening and treatment activities.

In the mid and late 1990s, DMAHS calculated the screening rates of Medicaid-enrolled children by counting the number of reimbursement claims submitted to it by the laboratories analyzing the blood tests. DHSS tracked the name and location of children with BLLs equal to or greater than 20μg/dL, based on reports from the same laboratories. It also tracked the completion, but not the initiation, of environmental investigations and abatements, using information provided to it by local health departments.[29]

The Universal Screening Law, however, requires DHSS to track *all* lead screening activities, not just those for children with elevated BLLs. Shortly after the Law's passage, DHSS entered into an agreement with the state's Office of Information Technology to develop a more sophisticated surveillance system to enable it to meet the Universal Screening Law's data collection and reporting mandates. The Office was to have completed the system by June 30, 1999, but was unable to do so because of hardware compatibility problems, staff turnover, and other state priorities. By the end of 2000, some software had been developed, but the system itself still was not in place.[30]

Although DHSS had intended to wait until the Office of Information Technology had completed the new system before beginning to collect the additional required data, it decided that it could wait no longer. In June 1999, it advised all laboratories analyzing lead blood screens to report all results (not just those over 20μg/dL) to DHSS. Without the necessary technology to handle the large influx of laboratory reports, six temporary data entry staff and more than two dozen other departmental staff spent much of 2000 manually putting approximately 60,000 test results into the system.[31]

C. No coordinated statewide education program

As of 2000, neither DMAHS nor DHSS had any organized plan for educating parents and caregivers about the importance of blood lead tests. Local health department officials, social workers, day care staff, and others who worked with families in high-risk communities believed that if parents and caretakers were properly educated, they would have their children screened. Yet educational efforts were minimal, hampered by a lack of coordination and funding.

DMAHS periodically sent targeted outreach letters, health promotion flyers, and lead stuffers to Medicaid-enrollees by mail. In meetings with the ACLU, however, it conceded that education by mail was not effective. Many letters and mailers were returned because families had moved. Some parents had limited reading skills. Other parents had more pressing concerns and did not open their mail on a regular basis.

Under the Universal Screening Law, DHSS is required to conduct a public information campaign about the need to test children for lead.[32]

In 2001, however, DHSS asserted that statewide public education was not its responsibility. It claimed that it had no budget for mass communication and limited funds for printing educational materials. Instead, it contended, statewide education was the responsibility of the Office for the Prevention of Mental Retardation and Developmental Disabilities, a division of DMAHS' parent agency, the Department of Human Services.[33]

The budget of the Office for the Prevention of Mental Retardation and Developmental Disabilities was so small and its mandate so broad that its ability to conduct any type of state-wide education effort on lead poisoning was severely limited. In each of fiscal years 1999, 2000, and 2001, the state legislature allocated slightly less than $1 million to the Office to enable it to educate the public on sixteen different preventable causes of disabilities. Of this amount, $200,000 was specifically earmarked for lead poisoning prevention education. The Office disseminated these funds in grants of between $10,000 and $50,000 per year, to local government agencies, community groups and non-profit organizations.[34]

D. No strategic lead-screening plan

Research has shown that in urban areas, certain zip codes and census tracts are more toxic than others. Most lead poisoning occurs within these neighborhoods, and very little occurs outside of them.[35] As of 2000, neither DHSS nor DMAHS had identified these areas; neither DHSS nor DMAHS had identified the children at greatest risk of lead poisoning; and neither DHSS nor DMAHS had engaged in any type of focused or strategic planning to ensure that those children received the lead blood tests to which they were legally entitled.

In fact, in a letter dated January 23, 2001, DHSS informed the ACLU that although the Universal Screening Law required DHSS to

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develop a comprehensive plan to control lead poisoning, DHSS was not responsible for developing a strategic outreach or screening plan. It claimed that drafting such a plan was the responsibility of the Interagency Task Force on the Prevention of Lead Poisoning.[36] Established in 1988, the Interagency Task Force had been designed to facilitate collaboration among the relevant state agencies and community groups involved in lead poisoning prevention.[37] Although the group met six times per year, meetings consisted of little more than brief presentations by agency and community representatives. Collaborative planning and implementation were inhibited by the fact that agency decision-makers rarely attended the meetings.

With respect to strategic screening plans, the Interagency Task Force had produced a document entitled, "Lead Poisoning Prevention Action Agenda" in 1989 and a second document entitled, "Recommendations for the Primary Prevention of Lead Poisoning" in 1995.[38] Neither was a plan for ensuring that the children at greatest risk of lead poisoning received lead blood tests.

E. No enforcement activities

Of 44 states responding to a survey by the National Conference of State Legislatures in 2000, almost all reported that doctors were one of the most significant barriers to screening. They did not consider lead poisoning to be a problem in their jurisdiction; they were

unaware of the federal or state laws mandating screening; or they refused to provide screening in their offices because drawing blood from a young child required too much staff time.[39]

In 2000, sample record reviews conducted by the Peer Review Organization of New Jersey (PRONJ), data generated by DMAHS for submission to the federal Centers for Medicaid and Medicare Services, and anecdotal information confirmed that New Jersey's Medicaid providers were not testing children for lead. Instead, many doctors were referring children to off-site laboratories to be screened but neglecting to ensure that the children actually went.[40] As a result, during state fiscal year 1999, 37% of all Medicaid-enrolled children ages one and two had some contact with a medical professional during state fiscal year 1999, but only 14% received a lead screen. During state fiscal year 2000, 42% had at least one contact with a medical professional, but only 25% received a lead blood test.[41]

Despite these statistics, neither DHSS nor DMAHS took any meaningful action to enforce the screening and treatment mandates of the state Universal Screening Law or the Medicaid Act. Neither agency audited health care providers to determine who was testing children for lead and who was not. In fact, DHSS did not even have a single complete list of New Jersey providers.[42] Although 85% of Medicaid-enrollees received health care services from Medicaid HMOs,[43] the contracts between DMAHS and the HMOs did not describe in any detail the responsibilities of the HMOs and the providers with respect to screening and treatment and did not impose sanctions for failure to provide such services.[44]

Although DHSS, DMAHS and the local health departments shared responsibility for treating lead burdened children, there were no written guidelines setting forth how the agencies were to interface with each other. DHSS only monitored the provision of case management services to children with BLLs over 20μg/dL who had voluntarily enrolled in a Prevention Oriented System for Child Health (POrSCHe) program. As of 2000, only 11 of the State's 114 local health departments had such programs.[45] Those 11 programs were providing services to only one-quarter of the 1,309 children identified as having BLLs over 20μg/dL during that fiscal year.[46]

While DHSS monitored the completion of environmental investigations and abatements, it did not monitor whether either were conducted in a timely manner. In fact, there were no guidelines setting forth the time periods within which environmental hazard assessments were to occur except for children at the highest levels of exposure.

DMAHS, on the other hand, did not monitor the treatment of any lead burdened Medicaid-enrolled children. As of June 2001, DMAHS had no idea whether any of the 653 Medicaid-enrolled children who had been identified as having BLLs equal to or greater than 20μg/dL during FY 2000 were receiving any case management services or environmental hazard assessments.

IV. PARTNERING TO ADDRESS BARRIERS

In response to these findings, the ACLU, ACNJ and other advocates threatened to sue DHSS and the state's Medicaid agency unless they began to take more aggressive steps to identify and treat lead poisoned children. The state's Medicaid agency, in turn, invited the advocates to work collaboratively to remedy identified problems. As a result of this collaboration, DMAHS made a number of significant changes.

Although DHSS participated in early discussions regarding these changes, it did not play an active role in their implementation and, as will be described in more detail later on, actually delayed the implementation of some initiatives.

A. Changes to the Medicaid contract

As previously stated, New Jersey's Medicaid HMO contracts made no specific references to the Medicaid Act's screening and treatment mandates. In late 2000, after consulting with George Washington University's Center for Health Services Research and Policy, however, DMAHS revised the contract to require, among other things, that each HMO:

- Develop a lead screening program that ensures that every Medicaid-enrolled child receives regular and periodic verbal risk assessments and lead blood screens between the ages of 9 and 18 months, again between the ages of 18 and 26 months, and as indicated by the results of the verbal risk assessment;[47]

- Pay providers on a fee-for-service basis for each lead screen performed in the provider's office;[48]

- Reach out by mail at least twice per year to the parents of children who have not yet been screened and implement corrective action plans for HMO staff to reach those parents who do not respond;[49]

- On an annual basis, notify providers with lead screening rates of less than 80% of their responsibility to provide lead screens and, with those providers, develop corrective action plans to increase their screening rates;[50]

- Establish lead case management programs and written case management plans for every child with a BLL equal to or greater than 10μg/dL;[51]

- Provide DMAHS with a plan, at the beginning of each year, setting forth the steps the HMO will take to improve its lead screening rates.[52]

It further revised the contract to permit DMAHS to impose financial sanctions against any HMO that failed to screen at least 80% of their members under the age of three during any 12-month contract period. HMOs with screening rates of less than 60% are subject to mandatory fiscal sanctions. HMOs with screening rates between 60 and 80% are subject to discretionary sanctions.[53]

To assist the HMOs in meeting the above contract requirements, DMAHS began to provide them with monthly lists of children who had not yet been screened and to meet with them quarterly to discuss contract compliance. In 2004, DMAHS levied its first lead testing-related sanctions against the HMOs based on fiscal year 2001 data. Additional sanctions were recently levied based on data from 2002.[54]

B. Annual audits of Federally Qualified Health Care Centers

In 2000, DMAHS conducted the first of a series of annual audits of the state's 15 Federally Qualified Health Care Centers (FQHCs) to determine the extent to which those facilities were screening the Medicaid-enrolled children who approached them for services.[55] FQHCs are federally funded health clinics, generally located in medically underserved areas, under contract with the federal Centers for Medicare and Medicaid Services to provide health care services to Medicaid-enrollees and the uninsured. After each audit, DMAHS reported the results to

the FQHCs, using the reporting process as an opportunity to educate the FQHC health care professionals about the need to test their young patients for lead.

C. Improving treatment

In 2002, DMAHS developed its own computerized information management system to track and monitor screening and treatment activities. Shortly thereafter, it began to use the system to provide HMOs with the previously mentioned monthly lists of children who had not been screened. By June 2005, it had entered into the system the approximately 2500 Medicaid-enrolled children under the age of 6 years who had BLLs equal to or greater than 10µg/dL as of January 1, 2005.

The Medicaid HMOs are required to put into the system the results of each child's initial and follow-up lead blood tests, the dates of certain case management activities, and the dates of any environmental hazard assessment. DMAHS reviews this data on a regular basis to ensure that all children are receiving the follow-up services to which they are entitled.

DMAHS also audits a random sample of case files from each of the Medicaid HMOs on a quarterly basis to determine whether children with BLLs equal to or greater than 10µg/dL are receiving case management services. If deficiencies are noted, the HMOs are required to develop corrective action plans.

In addition, the PRONJ annually reviews a random sample of medical records, at DMAHS' request, to determine whether Medicaid-enrolled children with BLLs equal to or greater than 20µg/dL are receiving case management services. The results of the most recent audit are set forth below:

Table 1
Percentage of lead burdened Medicaid-enrolled children receiving specific corrective services FY 2004

Services	% of children who received service
Referred to local health department	97%
Environmental investigation	79%
Physical examination	84%
Education regarding lead	82%
Psychosocial developmental evaluation	57%
Neurological evaluation	56%
Nutritional assessment	52%
Monthly blood tests until BLL falls below 20µg/dL	46%
Speech evaluation	42%

Children identified by the PRONJ as not having received case management services are referred directly to DMAHS.

D. Promoting on-site screening: introducing filter paper

Because so many children referred to off-site laboratories for screening never went, DMAHS, the ACLU and ACNJ formed a working group with representatives from the Medicaid HMOs to identify the reasons why doctors made such referrals.

When members of the New Jersey Chapter of the American Academy of Pediatrics were asked why they did not test for lead in their offices, they complained about the venipuncture method of testing, a method that DHSS had promoted after the passage of the Universal Screening Law. They stated that they did not have sufficient staffing resources to perform the test; the Medicaid HMOs did not adequately reimburse them for staff time; the procedure was too difficult; and parents were resistant to the test.[56]

Under the leadership of the Pediatric Medical Director of Horizon Mercy, Dr. William Silverman, the group elected to address these concerns by piloting the filter paper method of lead testing.

As compared to the venipuncture, the filter-paper method is easier to administer. Instead of drawing blood from a vein, a health care professional pricks a child's properly cleaned finger or toe and places that finger or toe over a square of specially treated filter paper, permitting two drops of blood to fall onto the filter paper. Once the sample dries, the filter paper is sent to a laboratory for analysis. All elevated BLLs must be confirmed with a venous draw.[57] In the mid-1990s, CDC expressed some initial concerns about the reliability of the filter-paper method, but by 1999, the technology had improved to such an extent that CDC endorsed the method.[58]

With the assistance of DHSS, the On-Site Screening Working Group selected two localities in which to pilot the filter paper method: Camden City, in southern New Jersey, and Irvington, in northern New Jersey. These areas were selected because they had many of the high-risk factors associated with childhood lead poisoning, including a significant percentage of pre-1950 housing, high unemployment, large numbers of families living in poverty, and large minority communities.[59]

DMAHS and the Medicaid HMOs identified approximately 150 Medicaid primary care providers with offices in the target areas, 59 of whom already did on-site screening using the venipuncture or capillary method of testing. The 150 were divided into groups of 15 to 25. Each Medicaid HMO assigned provider representatives to educate the different groups about filter paper testing.

Once health care providers had been introduced to the method, the New Jersey Chapter of the American Academy of Pediatrics, DHSS, DMAHS, and the Health Officers from the Irvington and Camden County Departments of Health sent letters encouraging those who did not already do so to provide on-site screening. The laboratory analyzing the filter paper provided the On-Site Screening Working Group with periodic reports, identifying the medical professionals who were using the filter paper method and providing the number of filter paper samples each had submitted for analysis. Representatives from DMAHS and the Medicaid HMOs made phone calls, and in some cases, in-person visits to those practice groups that continued to refer children to off-site laboratories for testing.

E. Community-based public education: targeting the day care community

Because DMAHS' efforts to educate Medicaid families by mail had been largely unsuccessful, DMAHS, the ACLU and ACNJ decided to pilot a community-based public education initiative. Under this initiative, day care center staff would be trained to educate the families of the children enrolled in their programs about the need for a lead screen and how to obtain one.

For the reasons outlined above, the DMAHS, the ACLU and ACNJ chose Irvington and Camden City in which to pilot the initiative. They invited the local health departments, Medicaid offices, local Child Care Resource and Referral Centers (CCR&R centers),[60] and Maternal and Child Health Consortia to form a working group to spearhead the initiative.

The Community Education Working Group targeted 36 day care centers in Irvington and 72 in Camden City.[61] Twenty-seven (27) of the Irvington centers and 35 of the Camden centers

were Abbott preschool programs, initiated in response to the 1998 ruling by the New Jersey Supreme Court in the lawsuit, *Abbott v. Burke.*[62] The Abbott preschool programs recommend that all children receive a physical examination within 90 days of enrollment and highly recommend that the examination include a lead blood test. Twelve of the Camden centers were Head Start programs. All Head Start programs mandate that all enrolled children receive lead screens.[63]

Between August 2002 and January 2003, the Community Education Working Group sponsored numerous training sessions at which day care directors, staff, and family outreach workers were trained on the dangers of lead poisoning and the need to have children tested for lead. The Chief Nurses for the Irvington Abbot preschool programs and the Camden County Head Start programs arranged for the Group's trainers to make presentations to the programs' staff at their annual pre-service trainings in August. Attendance was mandatory. The Working Group later received requests for and provided additional training on how to assist the families of lead burdened children, how to interpret the results of lead blood screens, what steps parents and caretakers can take to minimize the damage caused by lead poisoning, and the legal rights of and resources available to children who are lead burdened.

At the training sessions, the Community Education Working Group distributed numerous brochures, charts and resource guides to the day care staff for distribution to parents. Day care center staff subsequently reported, however, that the most effective written educational tool would have been a simple one-page flyer highlighting the dangers of childhood lead poisoning that they could post in their facilities or distribute to parents.[64]

Between September 2002 and January 2004, the Public Education Working Group asked day care directors to report the percentage of children screened, regardless of insurance status, to their local CCR&R centers. Roughly mid-way through that period, the Working Group asked the local health departments to modify the manner in which they conducted their annual immunization audits to include lead screening. State law requires local health departments to assist preschools and daycare facilities in implementing and enforcing state immunization requirements by conducting annual audits of school health records.[65]

F. Alternative site testing

In an effort to reach those Medicaid-enrolled children who did not visit their primary care physicians and who were not enrolled in a day care program, a third working group was formed to investigate the possibility of developing alternative lead testing sites. This working group explored the possibility of establishing such sites at WIC centers and in mobile vans that could be parked in front of day care centers or at neighborhood health fairs. At the time, however, neither option proved feasible. New Jersey WIC administrators felt that current staff was incapable of handling additional tasks and that there were no funds to hire more staff. The mobile vans were also too costly.

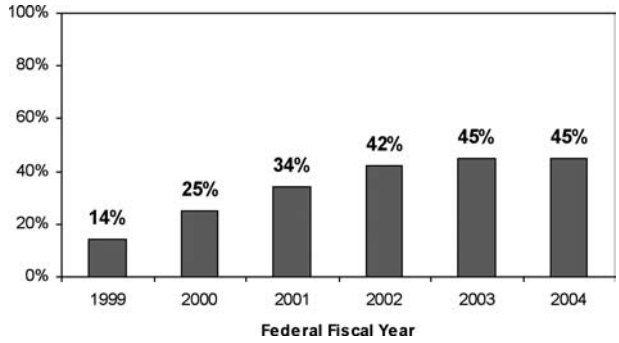
G. Results

By the end of 2004, the various reforms undertaken by DMAHS in response to or with the ACLU, ACNJ and other advocacy groups had resulted in a dramatic increase in the number of Medicaid-enrolled one and two-year olds who had been tested for lead. As a result, DMAHS decided to replicate the on-site screening and community education initiatives in four other municipalities — Jersey City, Paterson, Bridgeton, and Millville — using strategies employed in Irvington as a model.

1. Increased screening rates

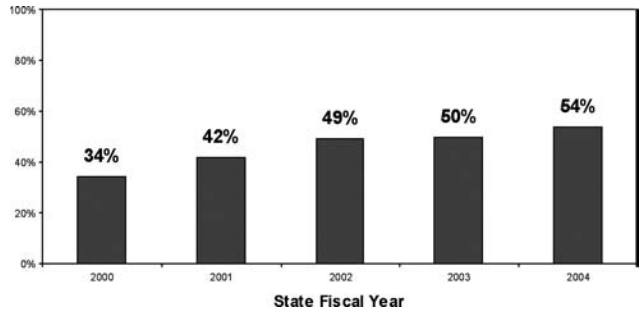
According to several different measures, the lead screening rate of Medicaid-enrolled children increased substantially between 2000 and 2004. As Table 2 illustrates, statewide screening rates of Medicaid-enrolled children, as reported by DMAHS to the federal Centers for Medicaid and Medicare, rose from 14% in federal fiscal year 1999 to 45% in federal fiscal year 2004.

Table 2[66]
Percentage of Medicaid-enrolled children between the ages of one and two tested for lead during the year indicated



As Table 3 illustrates, Medicaid HMO screening rates also increased during the same time period:

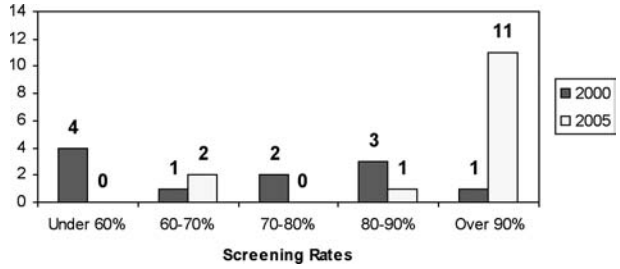
Table 3[67]
Percentage of children between the ages of 18 and 29 months, enrolled in a Medicaid HMO, and screened for lead during the year indicated



In state fiscal year 2000, individual HMO screening rates ranged between 23% and 39%.[68] In fiscal year 2004, they ranged between 46% and 60%.

As Table 4 illustrates, FQHC screening rates of Medicaid-enrolled children rose. Only one of the 11 centers audited in 2000 had a screening rate of over 90%. Eleven of the 14 centers audited in 2005 had screening rates of over 90%.[69]

Table 4
FQHC lead screening rates for Medicaid-enrolled children 2000 vs. 2005



As Tables 5 and 6 illustrate, the number of children screened in the two cities targeted for the on-site and community education initiatives increased.[70]

Table 5
Percentage of Medicaid-enrolled children 72 months old or younger who were screened during the year indicated below

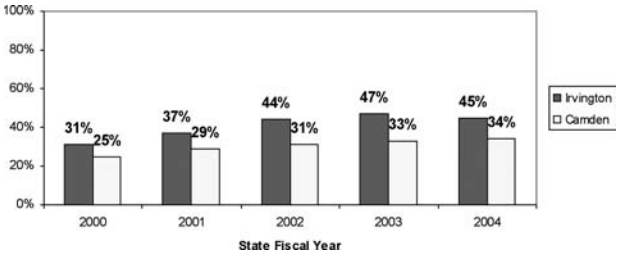
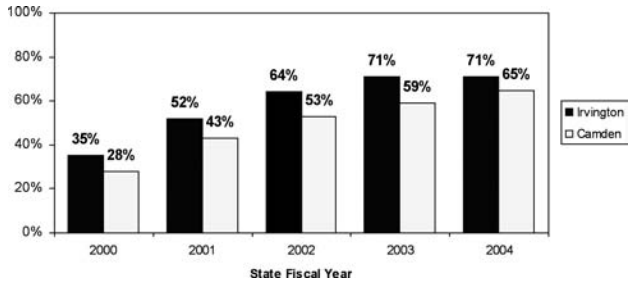


Table 6
Percentage of Medicaid-enrolled children 72 months old or younger who, as of the year indicated below, had been screened at least once in their lifetime



Because neither the on-site screening nor the community education initiatives were conducted pursuant to formal social science protocols, the Working Groups could not determine precisely the extent to which each contributed to the above increases. With respect to the on-site screening initiative, however, a survey conducted by DMAHS revealed a critical increase in the number of health care professionals testing for lead on-site. As of June 2002, 59 of the 150 Irvington and Camden City doctors included in the initiative provided screening on-site. As of January 2004, 121 tested for lead on-site.

Unfortunately, the Working Group was unable to determine whether the use of the filter paper method resulted in an increase in provider screening rates. Although DMAHS attempted to calculate provider screening rates, it could not do so in any reliable manner based on the data supplied to it by the Medicaid HMOs. DMAHS subsequently modified its contract with the HMOs to require them to maintain more specific provider data.

With respect to the community education initiative, 35 day care centers — the 23 Irvington Abbott preschools and the 12 Camden County Head Start programs — reported their screening results either to the ACLU or their CCR&R. In each of those centers, a significant number of the children enrolled during the 2002-03 academic year were tested for lead.[71] Eighty percent (80%) of the 1430 children in the Irvington Abbott preschool programs and 60% of the more than 1000 children enrolled in the Camden County Head Start programs were screened. Sixteen of the 23 Irvington centers had screening rates of over 80%. Seven of the 12 Camden County Head Start programs had screening rates of over 50%. Three of the seven had screening rates of over 70%.

2. Expanding the on-site and community education initiatives using Irvington as a model

By late 2004, DMAHS made the filter paper method of testing available to every health care provider with a Medicaid panel of 50 or more children. It is currently exploring ways to further encourage its use.

At the same time, DMAHS moved to replicate the on-site screening and community education initiatives in three other localities — Jersey City, Paterson and Bridgeton/Millville — beginning in June 2004. In so doing, it used Irvington, and the strategies developed there, as a model.

When interviewed by the ACLU at the conclusion of the community education initiative, the Irvington Abbott preschool programs attributed their successes to the fact that the day care center directors insisted that the children in their programs be screened for lead. Although Abbott preschool programs do not mandate lead blood tests like Head Start programs do, the Irvington Abbott preschool program directors voluntarily adopted center-specific screening policies. No child was excluded

from the program because he or she was not screened, but parents and caretakers were continuously reminded of the need to screen until their children were tested for lead.

The Irvington directors felt empowered to adopt these policies because of the strong support and encouragement they received from the Chief Nurse of the Irvington Abbot preschool programs and the Health Officer of the Irvington Health Department. The Chief Nurse and her staff provided all parents who enrolled children in an Abbott preschool program during the spring enrollment period with a health form. As of 2004, New Jersey did not require day care centers to use one standardized health form. Unfortunately, many of those in circulation, including the one distributed by the Camden County Abbott preschool programs, did not have a designated area in which providers were to record lead screening results. To circumvent this impediment, the Chief Nurse created her own form which did have such an area.

As they handed over the form, the Nurse and her staff informed parents that prior to the commencement of school in the fall, their children needed a comprehensive medical exam that included a lead screen. They highlighted with a yellow marker the area of the health care form on which the primary care provider was to record the results of the lead test. According to the Nurse, emphasizing the need to obtain a lead screen at this particular time was critical. Many families scheduled medical exams for their children during the summer months and asked providers to complete the forms at that time. If a lead screen was not included in that initial visit, the families were often reluctant or too pressed for time to return to the provider a second time later in the year simply for the lead screen.

The Chief Nurse maintained a computerized database that she used to track, among other things, immunizations and lead screens. If health forms were returned in the fall without lead results, the Chief Nurse informed the directors of the centers in which the children were enrolled. The directors, in turn, assigned to specific individuals within their centers — a nurse or in some cases a family outreach worker — the responsibility for ensuring that those children were screened. The Chief Nurse continued to monitor health forms and to provide the directors with the names of unscreened children throughout the course of the academic year.

To reinforce the importance of lead testing, the Irvington Health Department included lead in its immunization audits of the day care centers. Prior to the commencement of the audit, the Irvington Health Officer sent letters to the day care directors reminding them that Irvington was a high-risk area and informing them that lead would be included in the audit. She then contracted with the local CCR&R center, Programs for Parents, to conduct the audit. According to Programs for Parents, the immunization audits were most effective if the auditors prepared lists of the children at each day care facility who had not received the necessary immunizations or screens, provided those lists to the day care center directors, and asked the directors to inform the auditors when the children had obtained the vaccinations or screens. They believed that requiring day care center directors to report back on children without immunizations or screens was critical to ensuring the effectiveness of the audit.

To expand into Jersey City, Paterson and Bridgeton/Millville, DMAHS began training day care directors and staff in the summer and fall of 2004. With the assistance of Scholastic, Inc., it developed written educational materi-

Preliminary results indicate improvement. Within a few months, the screening rates of medical practice groups in Jersey City, Paterson and Bridgeton/Millville had increased an average of 13%.

als and posters which were distributed throughout the state to day care centers, family day care providers, WIC centers, doctor's offices, the Medicaid HMOs, and other community organizations for use during National Lead Awareness Week in October 2004. In addition, it persuaded local health departments to include lead in their immunization audits. At the same time, DMAHS' parent agency, the Department of Human Services (DHS), adopted a regulation requiring all day care facilities licensed by DHS' Division of Youth and Family Services to use DHSS' new Universal Health Form, which contains a designated space for lead test results.

DMAHS also began working with Medicaid providers in the localities. Specifically, it asked the Medicaid HMOs to determine the screening rates of the pediatric practice groups with the largest Medicaid-enrolled client-base in each locality (five in Bridgeton/Millville; six in Paterson and eight in Jersey City), and if their screening rates were less than 80%, to educate those groups on the need to screen all children for lead.

Preliminary results indicate improvement. At the end of state fiscal year 2004, the Jersey City, Paterson, and Bridgeton/Millville practice groups had screening rates of 58%, 58%, and 54%, respectively. By the end of the first quarter of fiscal year 2005, their rates had increased to 72%, 66%, and 68%, respectively.

V. DHSS

DHSS initially refused to play an active role in DMAHS' reforms or to initiate any of its own. In fact, during the ACLU's five-year history with New Jersey's childhood lead poisoning prevention program, DHSS' actions frequently frustrated DMAHS' ability to move forward. In late 2003, for example, the single individual responsible for DHSS' surveillance system moved to another position within DHSS. His position remained vacant for approximately nine months before DHSS hired a replacement. During that period, DMAHS had no access to data maintained by the system to determine the numbers of Medicaid-enrolled children who had or had not been screened.

In late 2002, the one nurse who purportedly oversaw the provision of case management and environmental assessments by local health departments and POrSCHe programs retired. Her position remained vacant until late 2004. During that period, no one at DHSS exercised any oversight over those programs. Her replacement reportedly discovered, among other things, that some local health departments were not conducting environmental hazard assessments in the manner contemplated by the Universal Screening Law and that others were using environmental hazard inspectors, instead of trained social workers or nurses, to provide case management services.

Again in 2003, the ACLU asked DHSS to modify index cards it distributed to day care centers to facilitate immunization audits. Because, at that time, different day care programs and pediatric groups used different health forms, directors and staff were encouraged to transfer immunization information from the health forms onto the index cards. When conducting the audit, the auditors only

reviewed the cards, not the original health forms. The card, however, did not contain a space for lead test results. While the Irvington Health Officer, acting on her own initiative, modified the cards to include lead without prior DHSS approval, the Camden Health Officer would not act without authorization from DHSS. DHSS considered the issue for almost one year before finally agreeing to modify the cards.

In 2003, three years after the ACLU's initial involvement with New Jersey, the CDC increased its programmatic demands on states that received CDC funding for lead poisoning prevention, including New Jersey. Among other things, it required recipients of funds for fiscal year 2003 to develop a plan to eliminate childhood lead poisoning by 2010; a targeted statewide screening plan; a statewide childhood lead surveillance system; and a written case management plan to reduce injury to lead burdened children. In return, it offered to provide these states with additional technical and scientific assistance.[72]

The presence of the CDC, continued pressure from the ACLU, the visible success of DMAHS' collaboration with the ACLU and ACNJ and a 2004 change in the leadership of its lead program resulted in DHSS finally taking action. In 2003, DHSS established four regional coalitions to coordinate lead education activities throughout the state under the supervision of a full-time lead educator hired in 2000.[73] In 2004, it published the Childhood Lead Poisoning Elimination Plan mandated by the CDC and called for an increase in the percentage of children screened by two years of age from 40% to 85%.

Also in 2004, DHSS:

- Required local health department recipients of State Public Health Priority Funding to use some of that money to promote or provide lead screening and treatment;[74]
- Purchased 100 portable lead analyzers for distribution to walk-in and community-based health clinics in 16 high-risk municipalities;[75]
- Announced its intention to purchase 44,000 lead dust testing kits for distribution to pregnant women and new mothers living in pre-1978 housing;[76]
- Funded and/or participated in two different pilot projects to provide on-site lead testing at WIC sites in Newark;[77]
- Developed and piloted a tool kit for physicians and their staffs to encourage pediatric practices to conduct on-site blood lead testing;[78] and
- Abandoned its efforts to work with the State's Office of Information Technology to develop a functional surveillance system. Instead, it entered into a contract with an outside vendor to install a system similar to that used by North Carolina's lead poisoning prevention program.[79]

While DHSS is to be commended for taking action, it has permitted some of these initiatives to stagnate. For example, at least two of the four regional lead coalitions floundered because DHSS, while providing them with funding, failed to provide them with necessary direction and guidance. They had little understanding of their mission or how to obtain the cooperation of necessary local agencies, organizations and advocates. Recently, the lead health care educator stated that these two coalitions have spent most of the last two years coaxing coalition members to the table.

With respect to the Elimination Plan, DHSS has yet to publish an implementation plan setting forth the steps that it and other state agencies will take to achieve the goals set forth in the Plan, the individuals responsible for those steps, the time periods within which they will be accomplished and the cost of those steps to the state. With respect to Public Health Priority Funds, DHSS has not adequately emphasized to the local health departments the degree to which they are to prioritize childhood lead poisoning prevention in their expenditure of such funds. In fiscal year 2005, local health departments allocated to childhood lead poisoning prevention only $77,000 of the more than $2,400,000 available to them.[80] With respect to the portable lead analyzers and dust wipe kits, DHSS has failed to distribute them in a timely manner. In May 2005, some portable lead analyzers were recalled because recent tests showed their results to be only 75% accurate.[81] As of September 2005, only 5,000 of the 44,000 lead dust wipe kits had been distributed, 230 had been returned for analysis, and 59 had tested positive for lead.[82] With respect to the physician tool kits, DHSS does not have the funding to reproduce and distribute them.

In addition, DHSS has made little meaningful effort to coordinate its activities and the activities of the regional lead coalitions with DMAHS' attempts to expand its on-site screening and community education initiatives. There can be no doubt that if DHSS and DMAHS simultaneously promoted an on-site screening initiative, the availability and use of portable lead analyzers, a community education initiative capitalizing on the local expertise and contacts of the regional lead coalitions, and the availability of dust-wipe kits in the same high-risk towns and municipalities at the same time, DHSS and DMAHS would have a far greater impact than they have acting alone.

VI. CONCLUSIONS AND RECOMMENDATIONS

Childhood lead poisoning in New Jersey remains as much a problem today as it was in 2000. The CDC estimates that approximately 1.6% of all children between the ages of one and five living in the United States have elevated BLLs.[83] In October 2004, DHSS reported that 3% of all children tested during state fiscal year 2003 had elevated BLLs — almost twice the national average. In Newark and Trenton, 8% of all children tested were lead burdened. In the city of East Orange, and the municipality of Irvington, approximately 9% of all children tested were lead burdened.[84]

Despite the progress that has been made to date, New Jersey has much work to do if it wishes to meet its goal of screening 85% of all one and two-year olds by 2010. Unfortunately, some of the institutional barriers described earlier continue to exist. Those barriers must be addressed and resolved if New Jersey is to continue to increase its screening rates.

A. Continued lack of leadership

The most significant impediment is the continued lack of state leadership. There is no entity or individual within state government to hold DHSS accountable for its failure to implement the Universal Screening Law in a timely manner. There is no entity or individual within state government to ensure the institutionalization of the changes made in response to pressure from the ACLU or the CDC and to continue to push for reform. There is no entity or individual within state government to ensure coordination between DHSS, DMAHS, and the other state agencies engaged in childhood lead poisoning prevention. The ACLU, ACNJ, LSNJ, and the Office of the Child Advocate recommend that:

Recommendation 1: In early 2006, the governor elected in November 2005 proclaim that the elimination of childhood lead poisoning by 2010 will be a priority of his administration.

Recommendation 2: Early in 2006, the new governor designate an individual in his office to assume leadership of the state's childhood lead poisoning prevention program, to coordinate the efforts of DHS, DMAHS, and other state agencies involved in childhood lead poisoning prevention and to move those efforts forward.

B. Continued lack of meaningful data

Although DHSS recently contracted with an outside vendor to develop a surveillance system, DHSS anticipates that the system will not be fully operational until June 2006. Thus, almost ten years after the New Jersey State Legislature passed a law requiring DHSS to develop a surveillance system, DHSS still does not have one. As a result, the type of data DHSS generates and makes public is extremely limited, as is its understanding of the trends and patterns of exposure within the state.

According to DHSS' most recent statistics, almost three-quarters of all reported cases of childhood lead poisoning fall within the jurisdiction of the following 13 local health departments: Newark, Paterson, Irvington, East Orange, Jersey City, Middlesex County, Elizabeth, Passaic City, North Bergen, Trenton, Plainfield, Cumberland, and Camden County.[85] Yet DHSS has not publicly identified the most toxic neighborhoods and communities within those jurisdictions. According to its Elimination Plan, this data will not be made public until June 2007.[86]

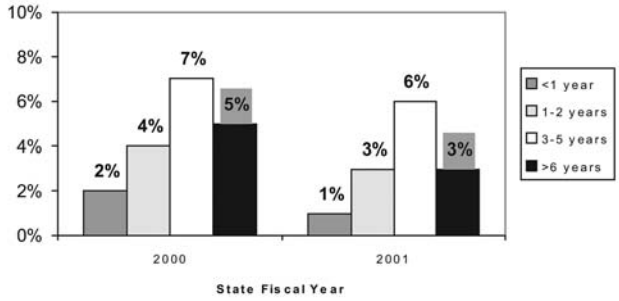
In addition, DHSS appears to have little understanding of the children being screened and the children with elevated BLLs.

Childhood lead poisoning in New Jersey remains as much a problem today as it was in 2000. The percentage of lead burdened children residing in New Jersey is almost twice the national average.

DMAHS reports that approximately one-third of the children who were identified as lead burdened in state fiscal year 2003 were Medicaid-enrolled. Who are the other children? Are they privately insured, uninsured, or eligible for Medicaid and simply not enrolled?[87] Are they African-American, West Indian, Caucasian, or recent immigrants from other localities?

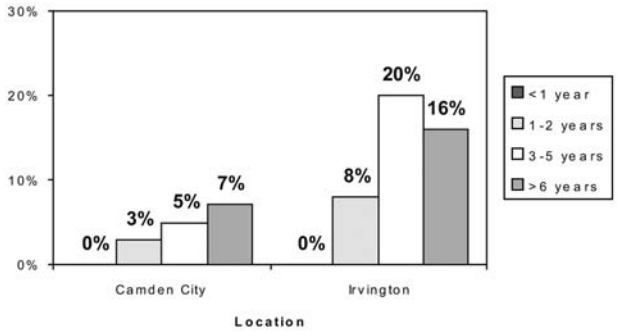
Are DHSS and DMAHS even targeting the right age groups? According DHSS, the results of lead tests administered during state fiscal years 2000 and 2001 reveal that three, four, and five year olds are more likely to be lead burdened than one and two-year olds. DHSS has not made similar data for fiscal years 2002 and 2003 publicly available.

Table 7[88]
Percentage of children tested during the year indicated who had BLLs equal to or greater than 10μg/dL, categorized by age



Data generated by DMAHS at the end of fiscal year 2002 for Medicaid-enrolled children in Camden City and Irvington reveals the same:

Table 8
Percentage of Medicaid-enrolled children tested for lead who had BLLs equal to or greater than 10μg/dL, categorized by age
May 2002



The ACLU, ACNJ, LSNJ and the Office of the Child Advocate recommend that:

<u>Recommendation 3:</u> The governor make immediately available to DHSS the resources necessary to ensure that it has a functional information management system capable of producing necessary data no later than June 30, 2006.

<u>Recommendation 4:</u> With the data they currently have, DHSS and DMAHS make available to the public, by January 1, 2006, the zip codes within the jurisdictions of the 13 local health departments that have the highest incidents of childhood lead poisoning, and a demographic profile of those children who are being screened and those children known to have elevated BLLs.

C. Continued lack of meaningful targeted outreach plan

Because the risk for lead exposure is not distributed evenly throughout the population, the CDC recommended in 1997 that states target high risk neighborhoods and children for additional educational and screening activities.[89] Yet neither DHSS nor DMAHS has developed a targeted education or screening plan. On more than one recent occasion, DHSS has commented that New Jersey does not need such a plan because the Universal Screening Law requires that all children be screened.

Such a comment ignores the purpose behind targeted plans. Even in a state that requires universal screening, not all children are equally at risk of lead poisoning. Targeted plans, among other things, ensure that limited state and local financial and administrative resources are wisely and strategically spent so that the public health officials reach the largest number of children at the greatest risk and that taxpayers, who are funding the state's lead poisoning prevention efforts, receive the greatest return for their money.

As previously mentioned, DMAHS and DHSS have not effectively collaborated on efforts to educate the public and increase screening. The Elimination Plan acknowledges that educational efforts have been disjointed and have not reached "New Jersey's diverse ethnic and cultural populations."[90] While DMAHS is promoting filter paper screening, DHSS is promoting portable lead analyzers and dust wiping kits. While DMAHS is auditing Medicaid providers to determine which ones need to be educated on the screening and treatment mandates of the Medicaid Act, DHSS is doing little to educate those recalcitrant doctors who service the privately insured and the uninsured about the screening and treatment mandates of the Universal Screening Law.

The ACLU, ACNJ, LSNJ, and the Office of the Child Advocate recommend that:

Recommendation 5: By April 1, 2006, DHSS and DMAHS, working together, develop and publish a plan to increase the educational and screening activities in the high-risk zip codes identified in response to Recommendation 4, with particular emphasis on those groups of children, defined by Medicaid-status, age, gender, race, and ethnicity, who reside within the zip codes and are not being screened.

At a minimum, the plan should set forth as one of its goals the screening of all children enrolled in a day care program or who visit a health care professional in the targeted areas, and describe the specific steps that DHSS and DMAHS will take to build on the lessons learned from DMAHS' reform initiatives. Specifically, it should describe the steps that DHSS and DMAHS will take to:

a. Ensure that licensed day care programs that enroll children residing in the high-risk zip codes adopt screening policies and a uniform record keeping system to track those who have been screened and those who have not; collaborate with local school districts to mandate that all children enrolling in Abbott pre-school programs receive lead screens; and lobby for the passage of legislation that would require all children attending day care programs to be tested for lead.[91]

b. Ensure that regional lead coalitions develop and implement programs to provide regular and periodic training to all day care directors, staff, family outreach workers, and any other interested organizations and entities in the high-risk zip codes on how to educate parents about the dangers of lead poisoning and the need for a lead screen.

Lead burdened children are still not receiving the corrective treatment and services to which they are legally entitled.

c. Ensure that the 13 local health departments previously identified include lead in their immunization audits, conduct those audits on an annual basis and follow auditing protocols utilized by the Irvington Health Department and Programs for Parents.

d. Identify medical practice groups, community health clinics, FQHCs and FQHC-look-alikes that service the Medicaid-enrolled and the uninsured in each of the targeted areas and make available to them all reputable methods of testing for lead, including the filter paper method and the portable lead analyzers. (To date, DHSS has refused to make the filter paper method of testing available to local health departments.)

e. Audit, or in the case of DMAHS, continue to audit health care providers, FQHCs, community health centers, FQHC look-alikes, and local health departments on a periodic and regular basis to determine their screening rates, and provide remedial and continuing education to those professionals, practices, clinics, and centers that have screening rates lower than 80%. The state Universal Screening Law requires doctors to screen. Their failure to do so is a violation of that law.

f. Explore the possibility of withholding of monetary reimbursement from Medicaid health care professionals who fail to screen at least 80% of the

Medicaid-enrolled one and two-year olds who come to them for medical services.

In addition, the plan should provide for aggressive outreach to those families whose children do not visit health care professionals or are not enrolled in childcare or day programs.

Recommendation 6: Starting in October 2006, DHSS and DMAHS issue semi-annual progress reports to the public setting forth the steps they have taken to date with respect to the implementation of the plan.

D. Failure to treat

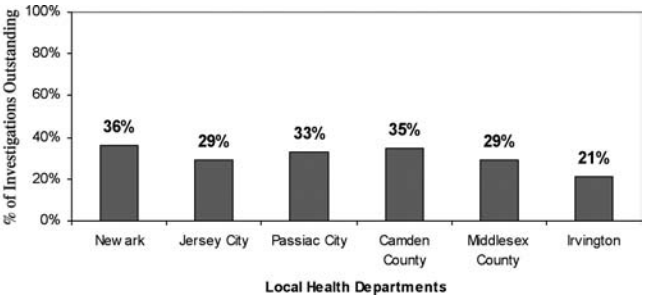
Lead burdened children are still not receiving the corrective treatment and services to which they are legally entitled. There are still no written guidelines instructing local health departments how to interface with the Medicaid HMOs with regard to the provision of case management services. There are still no written guidelines defining best practices for local health departments in terms of follow-up blood testing, case management services and environmental hazard assessments.

In direct violation of the Universal Screening Law, children known to have persistent BLLs of between 15 and 19µg/dL are still not receiving case management services from their local health departments. Although the Elimination Report states that DHSS will seek to obtain the resources to provide such children with services, it does not state when or how.[92]

The degree to which children with BLLs equal to or greater than 20µg/dL are receiving follow-up testing and case management services from local health departments is unclear. As of April 2005, less than one-half of the roughly 800 children known to have BLLs over 20µg/dL were enrolled in POrSCHe programs.

By the end of the most recent state fiscal year for which data is available, local health departments had completed only 71% of the mandated environmental assessments,[93] and landlords and property owners had abated only 35% of the properties with identified lead hazards.[94] As Table 9 illustrates, of the 13 local health departments in highest risk areas, several had significant backlogs.

Table 9
Percentage of environmental hazard assessments outstanding at the end of fiscal year 2003[95]



The ACLU, ACNJ, LSNJ and the Office of the Child Advocate recommend that:

Recommendation 7: By April 1, 2006, DHSS and DMAHS, working together, develop and publish a plan to ensure that all lead burdened children receive, in a timely manner, the follow-up blood testing, case management services, and environmental hazard assessments to which they are legally entitled.

Recommendation 8: Starting in October 2006, DHSS and DMAHS issue semi-annual progress reports to the public setting forth the steps they have taken to date with respect to the implementation of the plan.

Endnotes

[1] *See* Shilu Tonig, "Declining Blood Lead Levels and Changes in Cognitive Function During Childhood," 280 *JAMA* 1915 (Dec. 9, 1998).

[2] http://www.manbir-online.com/diseases/lead.htm. *See* Carrie Farmer, *Lead Screening for Children Enrolled in Medicaid: State Approaches,* Forum for State Health Policy Leadership, National Conference of State Legislatures, at 2 (2001).

[3] *Screening Young Children for Lead Poisoning: Guidance for State and Local Public Health Officials,* Centers for Disease Control and Prevention, at 41-42 (Nov. 1997).

[4] *Another Link in the Chain, State Policies and Practices for Case Management and Environmental Investigation for Lead-Poisoned Children,* Alliance to End Childhood Lead Poisoning and The National Center for Lead-Safe Housing, at 23 (June 1999).

[5] *The Foundations of Better Lead Screening for Children in Medicaid,* Alliance to End Childhood Lead Poisoning, at 3 (April 2001). Generally, symptomatic lead poisoning does not develop until a child's blood lead level exceeds 80 micrograms of lead per deciliter of whole blood (µg/dL) - an extremely dangerous level. *See* http://www.manbir-online.com/disease/lead.htm.

[6] 42 U.S.C. §§ 1396a(a)(43)(B), 1396d(r)(1)(B)(iv); 42 C.F.R. 441.56(b), 441.59(a); *State Medicaid Manual,* Centers for Medicaid and Medicare Services, United States Department of Health and Human Services, at § 5123 (1993).

[7] N.J.S.A. § 26:2-137.4; N.J.A.C. § 8:51A-2.2. As of 2000, New Jersey was one of three states that had passed legislation requiring universal lead screening. The other two were Rhode Island and Massachusetts. Carrie Farmer, *Lead Screening for Children Enrolled in Medicaid: State Approaches,* Forum for State Health Policy Leadership, National Conference of State Legislatures, at 6 (2001).

[8] Lead burdened, in this context, means having a blood lead level equal to or greater than 10µg/dL. *2003 Program Announcement,* Centers for Disease Control and Prevention, at App. IV

[9] Throughout this report, the term "screening" is used interchangeably with "lead blood test" or "blood test" or "lead test."

[10] Anne M. Wengrovitz, *Stuck in Neutral, States Neglect Lead Testing Duty to Children Served by Medicaid,* Alliance for Healthy Homes, at Appendix D (July 2005).

[11] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1, 1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at 14 (undated).

[12] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1,1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at 11 (undated).

[13] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1,1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at 11 (undated).

[14] 42 U.S.C. §§ 1396a(a)(43)(C), 1396d(a)(19), 1396d(r)(5); 42 C.F.R. 441.61; *State Medicaid Manual,* Centers for Medicaid and Medicare Services, United States Department of Health and Human Services, at § 5123. Because recent studies have found that even small amounts of lead can result in harm, some health care professionals advocate that any child with a BLL equal to or greater than 5µg/dL receive follow-up treatment. The CDC, however, has not altered its recommendations. Julie Gerberding, et. al., *Preventing Lead Poisoning in Young Children, A Statement by the Centers for Disease Control and Prevention,* United States Department of Health and Human Services, Public Health Services, at 2 (Aug. 2005).

[15] The Medicaid Act defines case management services as those that will "assist individuals eligible under the [Medical Act] in gaining access to needed medical, social, educational, and other services." 42 U.S.C. § 1396n.

[16] Managing Elevated Blood Lead Levels Among Young Children: Recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention, Centers for Disease Control and Prevention, at 22 (Mar. 2003).

[17] N.J.A.C. §§ 8:51-2.4, 8:51-3.1 to 8:51-4.5.

[18] As it deteriorates, lead-based paint peels and flakes, creating lead-contaminated dust that can adhere to walls, floors, carpets, toys, furniture, hands, and fingers. Carrie Farmer, *Lead Screening for Children Enrolled in Medicaid: State Approaches,* Forum for State Health Policy Leadership, National Conference of State Legislatures, at 2 (2001). An estimated 92% of all housing built before 1950 contains some lead-based paint. *See Putting the Pieces Together: Controlling Lead Hazards in the Nations Housing, Report of the Lead-Based Paint Hazard Reduction and Financing Task Force,* HUD-1547-LBP (July 1995). Among the 50 states, New Jersey ranks 8th in number and 13th in percentage of pre-1950 housing. At the end of state fiscal year 2000, 35% of New Jersey housing units had been built prior to 1950. Every one of the state's 21 counties had at least 10,000 pre-1950 housing units. *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July, 1999, to June 30, 2000,* New Jersey Department of Health and Senior Services, at 5 (undated).

[19] N.J.S.A. § 24:14A-7; N.J.A.C. ' 8:51-6.1. For purposes of the Universal Screening Law, abatement is defined as any activity or process designed to either mitigate or permanently eliminate lead-based paint or any other lead-related hazards on a premises, including, but not limited to, the removal of lead-based paint and lead-contaminated dust, the enclosure or encapsulation of lead-based paint, the replacement or removal of lead-painted surfaces, etc. N.J.A.C. § 8:51-1.3

[20] N.J.S.A. § 24:14A-9; N.J.A.C. ' 8:51-6.7.

[21] N.J.S.A. § 24:14A-10.

[22] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1, 1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at 17 (undated).

[23] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1, 1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at 17 (undated).

[24] In addition to DMAHS and DHSS, the Department of Community Affairs (DCA), the Department of Environmental Protection (DEP), the Department of Education and other divisions within DMAHS' parent agency, the Department of Human Services are involved in childhood lead poisoning prevention. See New Jersey Childhood LEAD Poisoning Elimination Plan, New Jersey Department of Health and Senior Services, at 3-4 (Oct. 2004). This report, however, only discusses DMAHS and DHSS, and only in connection with lead screening and treatment.

[25] N.J.S.A. §§ 26:2-132, 26:2-134.

[26] N.J.S.A. § 26:2-137.6(a).

[27] N.J.S.A. § 26:2-137.4(g).

[28] Carrie Farmer, *Lead Screening for Children Enrolled in Medicaid: State Approaches,* Forum for State Health Policy Leadership, National Conference of State Legislatures, at 10 (2001).

[29] Fifteen of the state's 114 local health departments maintain more detailed information on the types of services received by children with BLLs equal to or greater than 20µg/dL, *New Jersey Childhood Lead Poisoning Prevention Project, Application for Continued Funding of Cooperative Agreement, #US7/CCU218464-01, in response to CDC Program Announcement 01020, Part B,* New Jersey Department of Health and Senior Services, at Section C, Narrative Description of Proposed Project, p. 8 (April 2001), but DHSS did not make public use of the information. Two of these local departments (Newark and East Orange) have categorical lead programs. Another eleven (Burlington County, Camden County, Gloucester County, Irvington, Jersey City, Middlesex County, Monmouth County, Paterson County, Plainfield, Trenton, and Warren County) operate Prevention Oriented System for Child Health (POrSCHe) programs. These programs, which are funded by DHSS, are designed as "outreach case management models to assist primary health care providers." Enrolled families receive parenting skills training and counseling; specialized health education; regular health supervision visits to a primary care provider; assis-

tance in identifying health, nutritional, and developmental problems; and assistance in accessing community resources such as WIC, family planning, housing, education, job training, and other social services. *New Jersey 2004 Application/Annual Report Maternal and Child Health Services, Title V Block Grant Program,* New Jersey Department of Health and Senior Services, at 73 (April 2003).

[30] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1, 1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at 7 (undated).

[31] *New Jersey Childhood Lead Poisoning Prevention Project, Application for Continued Funding of Cooperative Agreement, #US7/CCU218464-01, in response to CDC Program Announcement 01020, Part B,* New Jersey Department of Health and Senior Services, at Section C, Narrative Description of Proposed Project, pp. 10-11 (April 2001).

[32] N.J.S.A. § 26:2-137.4(g). See N.J.S.A. ‘ 26:2-132(c) (requiring DHSS to stimulate “professional and public education concerning the need to test, detect and control lead poisoning . . .”).

[33] *See* Ltr from Celeste Wood, Assistant Commissioner, DHSS, to Robin L. Dahlberg, Senior Staff Attorney, ACLU, Jan. 23, 2001; *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2001, July 1, 2000 to June 30, 2001,* New Jersey Department of Health and Senior Services, at 30 (undated).

[34] These groups have included, among others, the Citizen Policy and Education Fund, the Camden County Council on Economic Opportunity Head Start, Rutgers Cooperative Extension, the University of Medicine and Dentistry of New Jersey, LSNJ, ACNJ, New Jersey Citizen Action, the Burlington County Health Department, and the City of Trenton. *Strategic Plan 2003-2008,* New Jersey Interagency Task Force on the Prevention of Lead Poisoning, at 18-23.

[35] N. Tips, *A Brief Guide to Options for Improving Medicaid Lead Screening,* Alliance to End Childhood Lead Poisoning, at 3 (Nov. 2002), citing M.J. Brown, E. Shenassa, and N. Tips, *Small Area Analysis for Childhood Lead Poisoning,* Alliance to End Childhood Lead Poisoning (2001).

[36] Ltr from Celeste Wood, Assistant Commissioner, DHSS, to Robin L. Dahlberg, Senior Staff Attorney, ACLU, Jan. 23, 2001.

[37] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 4 (Oct. 2004).

[38] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 4 (Oct. 2004).

[39] Carrie Farmer, *Lead Screening for Children Enrolled in Medicaid: State Approaches,* Forum for State Health Policy Leadership, National Conference of State Legislatures, at 6 (2001). *See Recommendations for Blood Lead Screening of Young Children Enrolled in Medicaid: Targeting a Group at High Risk,* Advisory Committee on Childhood Lead Poisoning Prevention, Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report, 49 (RR14) (Dec. 8, 2000); Nancy Tips, A Brief Guide to Options for Improving Medicaid Lead Screening, Alliance to End Childhood Lead Poisoning, at 15 (Nov. 2002).

[40] More than 50% of those members of the New Jersey Chapter of the American Academy of Pediatrics surveyed by the PRONJ in 2000 stated that they did not provide screening services in their offices. *2001 Pediatric Health Care Provider Lead Screening Survey, Technical Report R147,* PRONJ, at 11 (Mar. 2001). A survey of large Medicaid pediatric practices in Camden and Irvington concluded that 29% of the children in Camden and 45% of children in Irvington referred off-site for screening were never tested for lead. *Camden/Irvington Lead Screening Audits, Technical Report R226,* PRONJ, at 2, 4 (Aug. 2002). A similar survey of Medicaid pediatric practices in Jersey City and Paterson concluded that 51% of the children in Jersey City and 43% of the children in Paterson referred off-site for screening were never tested for lead. *JerseyCity/Paterson Lead Screening Audits, Technical Report R323,* PRONJ, at 3, 4 (Oct. 2003).

[41] Anne M. Wengrovitz, *Stuck in Neutral, States Neglect Lead Testing Duty to Children Served by Medicaid,* Alliance for Healthy Homes, at Appendices C and D (July 2005).

[42] *New Jersey Childhood Lead Poisoning Prevention Project, Application for Continuation of Funding of Cooperative Agreement, #US7/CCU218464-01, in response to CDC Program Announcement 01020, Part B,* New Jersey Department of Health and Senior Services, at Section C, Narrative, p. 12 (April 2001).

[43] Form HCFA-416: Annual EPSDT Participation Report, New Jersey, Federal Fiscal Year 2000.

[44] According to the CDC, doctors and HMOs are more likely to view the Medicaid Act's screening and treatment requirements as enforceable legal obligations if the contracts between the HMOs and state Medicaid agencies explicitly require lead blood testing and treatment. *Recommendations for Blood Lead Screening of Young Children Enrolled in Medicaid: Targeting a Group at High Risk,* Advisory Committee on Childhood Lead Poisoning Prevention, Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report, at 49 (RR14) (Dec. 8, 2000).

[45] *See* Endnote 29.

[46] POrSCHe Grant Progress Reports, 1/1/00-6/30/00, 7/1/00-12/31/00; *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1, 1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at 12 (undated).

[47] Contract Between State of New Jersey, Department of Human Services, Division of Medical Assistance and Health Services, and _____ , ("HMO Contract"), at IV-31. The contract can be found at http://www.state.nj.us/humanservices/dmahs/about_dmahs.html.

[48] HMO Contract, at IV-29.

[49] HMO Contract, at IV-35.

[50] HMO Contract, at IV-35.

[51] HMO Contract, at IV-36.

[52] HMO Contract, at IV-62.

[53] HMO Contract, at VII-30, 31.

[54] HMO EPSDT Sanction Tracking Report, revised 7/27/05.

[55] Where an FQHC has multiple offices, DMAHS audits the office serving the largest number of Medicaid-enrolled children.

[56] *2001 Pediatric Health Care Provider Lead Screening Survey, Technical Report R147,* PRONJ, at 6 (Mar. 2001).

[57] N.J.A.C. § 8:51-2.3

[58] In 1995, the CDC issued a "Dear Colleague" letter recommending against filter paper lead testing because the method resulted in a high number of false positives. Among other things, the filter paper itself contained unacceptably high levels of lead. Ltr. from Dayton T. Miller, Ph.D. and Robert L. Jones, Ph.D., Division of Environmental Health Laboratory Sciences, National Center for Environmental Health, dated July 18, 1995. In response to the letter, laboratories improved both the quality of the filter paper and the manner in which it was analyzed. At the same time, CDC established a proficiency-testing program at the Wisconsin State Laboratory of Hygiene (WSLH) to oversee laboratory practices and procedures. In 1999, CDC revised its position and issued a second "Dear Colleague" letter stating that "filter paper techniques [were] acceptable" as long as physicians sent their samples to be analyzed at laboratories participating in a certified proficiency-testing program. Ltr. from Dayton T. Miller, Ph.D. and Robert L. Jones, Ph.D., Division of Environmental Health Laboratory Sciences, National Center for Environmental Health, dated February 25, 1999. As of May 2002, there were five laboratories that analyzed filter paper, each of which participated in WSLH's proficiency-testing program. Ltr. to Arlene Gilbert, Attorney, ACLU, from Noel Stanton, Program Supervisor, Wisconsin State Laboratory of Hygiene, dated April 16, 2002. One of these laboratories analyzed the filter paper used in this initiative.

[59] Forty-two (42) percent of the housing in Irvington and 54% of the housing in Camden City was constructed prior to 1950. Each city had an unemployment rate more than twice that of the state. 44% of Camden City=s families

with children under the age of five and 22% of Irvington's families with children under the age of five lived in poverty. Between 80 and 90% of each city's population was minority. *New Jersey Childhood Lead Poisoning Prevention Project, Application for Continued Funding of Cooperative Agreement, #US7/CCU218464, in response to CDC Program Announcement 0300 for Childhood Lead Poisoning Prevention Programs,* New Jersey Department of Health and Senior Services, at Section II, Narrative, pp. 2-3 (March 2003).

[60] The CCR&R centers work with the New Jersey Department of Human Service's Division of Family Development to administer child care subsidies, provide resource and referral services, take steps to raise the quality of child care operations, and promote the development of additional child care capacity. See http://www.state.nj.us/humanservices/dfd/chldca.html.

[61] Of Irvington's roughly 4,900 children under the age of 5, approximately 1600 were enrolled in the 36 centers. Of Camden City's roughly 7,300 children under the age of 5, approximately 2,800 were enrolled in the 72 centers.

[62] Filed in 1981, the *Abbott* case challenged the inequality in funding between New Jersey's urban school districts and its affluent suburban districts. The Supreme Court's 1998 ruling mandated that the state establish high-quality preschool programs in the state's 30 highest-poverty school districts. While administered by the school districts in which they are located, the preschool programs were required to adhere to certain court-ordered mandates regarding classroom size, teacher qualification, and the provision of social and health services. *The Abbott Preschool Program: Fifth Year Report on Enrollment and Budget, October 2003, A Report of the Abbott Indicators Project,* Education Law Center, at iv (2003).

[63] 45 C.F.R. 1304.20 (requiring Head Start programs to obtain from a health care professional a determination as to whether every enrolled child has received age appropriate preventive and primary health care, including screens required by the Medicaid Act and the latest immunizations recommended by the Centers for Disease Control and Prevention).

[64] Materials distributed included those previously developed under the auspices of the state's Office for the Prevention of Mental Retardation and Developmental Disabilities, pamphlets and posters available free of cost from the Lead Awareness Program of the federal Environmental Protection Agency, *see* www.epa.gov/lead/leadpbed.htm, and booklets and growth charts developed by the Channing-Bete Company, a publishing company that produces easy-to-read, culturally sensitive, and competent educational materials on a wide range of public health issues. *See* www.channingbete.com.

[65] N.J.A.C. § 8:52 App. State administrative regulations require that preschools and day care centers maintain health and immunization records on every enrolled child. N.J.A.C. § 8:57-4.7

[66] Anne M. Wengrovitz, *Stuck in Neutral, States Neglect Lead Testing Duty to Children Served by Medicaid,* Alliance for Healthy Homes, at Appendix D (July 2005); Form CMS-416: Annual EPSDT Participation Report, New Jersey, Federal Fiscal Year 2004.

[67] HMO lead screening rates are based on both the number of lead screens reported to DHSS by the laboratories analyzing the results and HMO encounter data. See HMO EPSDT Sanction Tracking Report, dated July 14, 2005.

[68] *Comprehensive Lead Screening Study, Technical Report R225,* PRONJ, at Table 1, p. 12 (Apr. 2003).

[69] The DMAHS audit is a review of 50 randomly chosen records from each center. Some centers have more than one location.

[70] *Performance Measures 2 and 4 for Lead Screening Pilot Project Conducted in Camden and Irvington (June 2002-January 2004),* PRONJ, at 3-4 (June 2005) (Draft). The screening rates for Irvington and Camden were calculated by comparing the laboratory reports submitted to DHSS with DMAHS Medicaid enrollment lists. According to DMAHS, 50-60% of the matches that result from these comparisons are exact matches (i.e., birth date, name, and address correspond exactly). The remaining 40-50% are "probable" matches (some data corresponds exactly while other data might be slightly off).

[71] The Working Groups were unable to obtain any data from the Camden Abbott preschool programs. In 2003, parents filed suit against the Camden County Board of Education, which oversees the programs, alleging that the Board had failed to inform them that several schools had dangerously high levels of lead in their drinking water.

Under the federal Drinking Water Act, school districts must test their water for lead quarterly and remedy any problems. According to the suit, test results from 1999 through 2000 revealed unsafe lead levels. See Lavinia DeCastro, "Camden residents file lawsuit over lead in water at schools," *Courier Post* (March 13, 2003). Because of the suit, the Abbott preschool programs' Chief Nurse refused to speak publicly on any issue relating to lead. While she attended some Working Group planning meetings, she did not participate in those meetings.

[72] 2003 Program Announcement, at www.cdc.gov./nceh/lead/grants/pgmAnnouncement/PA2003.htm.

[73] The four coalitions are the Passaic/Bergen Regional Lead Poisoning Prevention Coalition (target areas are Bergen and Passaic Counties); the LEAP (Lead Education, Advocacy, and Prevention) Regional Coalition (target areas are 10 counties in northern and central New Jersey); the Monmouth/Ocean County Lead Poisoning Prevention Coalition (active in Monmouth and Ocean Counties); and the Southern Region Childhood Lead Poisoning Prevention Coalition (active in seven south Jersey counties, including Atlantic, Burlington, Camden, Cape May, Cumberland, Gloucester, and Salem).

[74] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 25, 26 (Oct. 2004); Guidelines and Requirements, Public Health Priority Funding, Eligible Activities - CY 2005, Attachment A, at 3 (funds are to be used by local health departments to "[a]ssure that all children are appropriately screened for lead poisoning" in accordance with Universal Screening Law; "[i]nclude lead screening in the audits of child immunization records at licensed child care facilities;" and "[p]rovide environmental investigations and case management follow-up of children with reported elevated blood lead levels . . .")

[75] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 21-25 (Oct. 2004). The 100 lead analyzers are to be distributed in Atlantic City, Bridgeton, Camden, East Orange, Elizabeth, Irvington, Jersey City, Montclair, Newark, New Brunswick, Orange, Passaic, Paterson, Perth Amboy, Plainfield, and Trenton.

[76] In January 2004, then-Governor McGreevey announced the allocation of $1 million to purchase the lead dust test kits. DHSS hopes to distribute the kits in 20 cities through a non-profit agency, Family Health Initiatives, and private providers. Those cities include Bridgeton/Millville, Vineland, East Orange, Irvington, Newark, Trenton, Orange, Paterson, Plainfield, New Brunswick, Montclair, Camden, Atlantic City, Passaic City, Elizabeth, Jersey City, and Perth Amboy. *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 29 (Oct. 2004).

[77] The Childhood Lead Poisoning Prevention Program of the Newark Department of Health and Human Services organized a pilot project using portable lead analyzers to screen children during visits to a designated WIC center. The University of Medicine and Dentistry of New Jersey organized another project using a phlebotomist to draw blood venously at another Newark WIC center. *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 23-4 (Oct. 2004).

[78] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 24-5 (Oct. 2004).

[79] This system has been sited as a model by the National Conference of State Legislatures' Forum for State Health Policy Leadership. Carrie Farmer, *Lead Screening for Children Enrolled in Medicaid: State Approaches,* Forum for State Health Policy Leadership, National Conference of State Legislatures, at 10 (2001).

[80] E-mail from Kevin McNally, Division of Local Public Health Practice and Regional Systems Development, New Jersey Department of Health and Senior Services, to Arlene Gilbert, ACLU Attorney, dated Sept. 13, 2005. *See also* http://nj.gov/health/lh/phpfform.htm.

[81] Ltr. from ESA, Biosciences, Inc., entitled "Product Recall Notice, LeadCare Blood Lead Testing System," dated May 19, 2005.

[82] E-mail from Maggie Gray, Coordinator, Primary and Preventive Health Care Services, New Jersey Department of Health and Senior Services, to Arlene Gilbert, ACLU Attorney, dated September 19, 2005.

[83] *Blood Lead Levels - United States, 1999-2002,* Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report, Vol. 25, No. 20, at 513-516 (May 27, 2005).

[84] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2003, July 1, 2002 to June 30, 2003,* New Jersey Department of Health and Senior Services, at 17-18, 43-44 (Oct. 2004).

[85] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 20 (Oct. 2004).

[86] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 18 (Oct. 2004).

[87] Roughly 10% of New Jersey's children under the age of 18 are uninsured. *Going Without: America's Uninsured Children,* prepared for the Robert Wood Johnson Foundation by the State Health Access Data Assistance Center and the Urban Institute, at 5 (Aug. 2005).

[88] *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2000, July 1, 1999 to June 30, 2000,* New Jersey Department of Health and Senior Services, at Table 5, p. 15 (undated); *Childhood Lead Poisoning in New Jersey, Annual Report, Fiscal Year 2001, July 1, 2000 to June 30, 2001,* New Jersey Department of Health and Senior Services, at Table 5, p. 15 (undated).

[89] Carrie Farmer, *Lead Screening for Children Enrolled in Medicaid: State Approaches,* Forum for State Health Policy Leadership, National Conference of State Legislatures, at 10 (2001).

[90] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 28 (Oct. 2004).

[91] In Maryland, state law requires that the parent or guardian of any child under the age of six in a child care program submit evidence that the child has been screened for lead within 30 days of the date of the child's entry into that program. Md. Code Ann. [Fam. Law], §§ 5-556.1, 5-580.2, 5-589.1.

[92] *New Jersey Childhood LEAD Poisoning Elimination Plan,* New Jersey Department of Health and Senior Services, at 26-27 (Oct. 2004).

[93] *Childhood Lead Poisoning in New Jersey, Annual Report,* Fiscal Year 2003, July 1, 2002 to June 30, 2003, New Jersey Department of Health and Senior Services, at Appendix 2, p. 49 (Oct. 2004).

[94] *Childhood Lead Poisoning in New Jersey, Annual Report,* Fiscal Year 2000, July 1, 2002 to June 30, 2003, New Jersey Department of Health and Senior Services, at 17 (Oct. 2004).

[95] *Childhood Lead Poisoning in New Jersey, Annual Report,* Fiscal Year 2000, July 1, 2002 to June 30, 2003, New Jersey Department of Health and Senior Services, at Appendix 2, pp. 46-49 (Oct. 2004).

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