Legal and Non-Legal Strategies to Improve Childhood Lead Screening Rates in Illinois and Ohio

The Problem

Despite the prevalence of lead in U.S. homes and infrastructure and the well-known harms associated with childhood lead exposure, lead screenings are not performed consistently. Without routine testing, lead poisoning is unlikely to be detected or treated and lead exposure is likely to continue, yielding cumulative and long-lasting adverse health impacts for affected children.

The U.S. Centers for Disease Control and Prevention (CDC) reported that in 2016, approximately 14 percent of Illinois children under age six were tested for lead.1 That same year, approximately 19 percent of Ohio kids under age six were tested.2 Although the CDC acknowledges limitations to this data3 and the data does not show how many kids have ever been tested (it only reflects 2016 testing), the numbers are alarmingly low: they signal an urgent need to increase lead screening rates to assure early detection of childhood lead poisoning. In addition, the data limitations highlight the importance of improving and standardizing nationwide surveillance of childhood lead testing and poisoning.

This brief examines existing legal screening requirements in Illinois and Ohio (including state laws and Medicaid requirements) and explores legal and non-legal strategies for improving lead screening rates in these states.

Introduction

Lead exposure remains the most significant and widespread environmental hazard for children in the United States, particularly those ages five years and under. The CDC estimates that more than four million American households include young children being exposed to high levels of lead, and that 500,000 children between one and five years old have elevated blood lead levels (BLLs).4 This extremely toxic, naturally occurring element is all around us: in the air, soil, and water, as well as in our homes.5 Lead adversely affects almost every organ in the body and is especially harmful to young children.5 High BLLs in children and adults can result in seizures, coma and death.7 However, even low BLLs in children (i.e., ≤5 micrograms per deciliter (µg/dL)) are associated with behavioral and learning problems (such as hyperactivity, inattention, and aggression), lower IQ, and developmental delays.8 Accordingly, the American Academy of Pediatrics, CDC and others have observed that there is no safe level of lead exposure.9
Common Sources of Childhood Lead Exposure

The primary sources of childhood lead exposure in the U.S. include lead-based paint and contaminated drinking water. Less prevalent lead exposure pathways include imported or cultural products such as candies, toys, toy jewelry, folk medicine, pottery and cosmetics. 10

The Consumer Products Safety Commission banned the use of lead-based paint in 1978; however, it is estimated that one in three U.S. homes (37.1 million) were built before 1978 and have lead-based paint somewhere in the building.11 Of these, an estimated 23 million have one or more lead hazards present. The prevalence of lead hazards varies by region, with the highest prevalence found in the Northeast and Midwest, including Illinois and Ohio.

Deteriorating lead-based paint and lead dust are the primary but not the only causes of lead exposure for U.S. children. Contaminated drinking water from the corrosion of lead solder, pipes and fixtures is another leading source of elevated blood lead levels in children. The U.S. Environmental Protection Agency (EPA), recognizing that lead is a toxic metal and harmful to human health even at low levels, has established a maximum contaminant level goal (MCLG) of zero for lead in drinking water.12 Yet as the Flint Water Crisis13 and incidents in Washington, D.C., Philadelphia, Chicago, and other cities underscore,14 the issue of contaminated drinking water persists in the U.S. An estimated 20 percent of total lead exposure in the U.S. could be related to contaminated drinking water.15

Importance of Childhood Lead Screening

Because there is no safe level of lead exposure, primary prevention—i.e., eliminating all sources of lead from the environment—is paramount. But until primary prevention efforts are widely and successfully implemented, childhood lead screening via blood lead testing is essential to preventing prolonged exposure and mitigating harmful effects. Indeed, an elevated blood lead test result should prompt immediate action to identify and remove or remediate sources of lead exposure. Elevated blood lead test results should also trigger appropriate follow-up medical care and any necessary behavioral health and/or learning support services.

From 2002 to 2010, the CDC’s Child Blood Lead Surveillance (CBLS) system reported that in the 43 states and Washington, D.C. that reported to the system, the blood lead screening rate for children aged one-two years increased from 22 percent to 33.4 percent, and over the same period the percentage of children with confirmed BLLs ≥10 µg/dL decreased from 9.3 percent to 2.0 percent. The percentage of one-two year old children with BLLs 5-9 µg/dL also decreased from 14.9 percent to 4.2 percent over the same period of time.16 Though BLLs in children have declined significantly over the past three decades, certain populations remain at an increased risk of elevated BLLs. Young children (especially those two years old or younger, in part because they are more likely to engage in hand-to-mouth behaviors), children residing in older homes (i.e., built before 1978), children in low-income households, and children from racial or ethnic minority groups have an elevated risk of childhood lead exposure.17 Children with low iron levels may also be at increased risk for lead absorption.18 Conducting lead risk assessments and screening at-risk children for elevated BLLs are among the most effective ways to identify children and geographic areas with elevated BLLs, detect emerging sources of lead exposure, and reduce the incidence of childhood lead poisoning.

A number of federal and state laws include explicit requirements relative to lead screening. Yet persistently low screening rates across the country mean that millions of children are never tested for lead.19 A lack of testing enables prolonged exposure to lead and hinders access to appropriate follow-up care. This issue brief examines legal and non-legal approaches for increasing childhood lead screening rates.

Background: Blood Lead Testing

Lead poisoning is generally detected by testing a child’s blood for the presence of lead. Blood samples for lead testing are usually obtained in one of two ways. One method is to obtain a capillary blood sample using a finger- or heel-stick test,
which often can be easily administered on-site at a pediatrician’s office, school nurse’s office, or other convenient location via a “point-of-care” test. A second method is to obtain a venous blood sample through venipuncture, which is more invasive and must be administered by skilled medical or laboratory personnel.20

Because capillary tests are more accessible and less painful than venous tests, they are a valuable method for conducting initial lead screenings. However, capillary tests are more likely to yield false positives, especially if the finger or heel is not properly cleaned. As a result, the American Academy of Pediatrics and the CDC recommend—and many states require—that elevated capillary lead levels should be confirmed by venous testing.21 Nevertheless, the American Academy of Pediatrics advises that an elevated capillary lead level indicates the presence of lead in a child’s environment even if the venous lead level is low and thus should trigger primary prevention (i.e., an environmental assessment and removal of lead hazards) and education.22

Note that confusion may arise regarding the difference between the terms “screening” and “testing.” This is because “screening” may refer to screening for risk factors of exposure (using a questionnaire) or screening for the presence of lead in a child’s blood (using blood lead tests).23 In this issue brief, we use the terms interchangeably to refer to screening children’s blood for the presence of lead via venous or capillary blood lead tests. We use the terms interchangeably because the laws cited within the brief use the terms interchangeably. When we discuss screening for risk factors of exposure using questionnaires, we will state this explicitly.

Lead Screening Requirements

**Medicaid**

Federal law requires blood lead testing as “appropriate for age and risk factors” for all children enrolled in Medicaid.24 As a component of the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit and as a result of a nationwide class action case25, the Centers for Medicare and Medicaid Services (CMS) specifically requires that all children enrolled in Medicaid receive at least two blood lead screening tests—one at age 12 months and again at age 24 months. In addition, children between 36 and 72 months of age must receive a blood lead screening test if they have not previously been tested for lead poisoning.26 This requirement cannot be satisfied by completing a risk assessment questionnaire, which is generally designed to evaluate the likelihood of exposure based on environmental and other factors.27 States must ensure that Medicaid-eligible families are aware of the EPSDT benefit and have access to required screenings and necessary services.28 The screening services cannot be subjected to cost sharing or prior authorization requirements.29

Though this universal screening requirement remains the default requirement for state Medicaid programs, in 2012 CMS amended its lead screening policy to allow states to request approval of targeted screening programs.30 To obtain CMS approval of a targeted screening program, state Medicaid programs must work with their state health department to develop an appropriate targeting methodology for focusing resources on populations with the highest level of risk.31 As of November 2016, Arizona was the only state with an approved targeted lead screening program.32

State Children’s Health Insurance Programs (CHIP) may or may not be required to provide EPSDT benefits depending on whether the program is provided separately or in combination with the state’s Medicaid program. Separate CHIP programs are not bound by the same requirements as Medicaid and are not required to provide universal lead screening.33 Nevertheless, CHIP programs must offer well-baby and well-child visits,34 which are defined as “regular or preventive diagnostic and treatment services necessary to ensure the health of babies, children and adolescents as defined by the State.”35 Moreover, states are prohibited from imposing cost-sharing measures on services associated with these visits, including routine physical examinations and associated laboratory tests recommended by the American Academy of Pediatrics (AAP) Bright Futures guidelines.36 The Bright Futures schedule recommends blood lead screening at 12 and 24 months of age for children at risk of exposure.37
Data reported from state agencies to CMS in 2015 indicate that only 38 percent of children ages one to two years old received a blood lead test. Though CMS believes that this data underreports actual blood lead tests since some children may receive tests through clinics funded by the CDC or state health departments (rather than being paid by Medicaid), the data nevertheless shows that many eligible and potentially lead-exposed children are not being tested. Moreover, reports by other governmental agencies and advocates have questioned the reliability of CMS data and have suggested that the data may over-report provision of lead testing and other EPSDT services, particularly in managed care settings, due to incomplete or vague reporting requirements.

Testing Methodology

Blood lead screening tests may be conducted using either a venous or capillary sample, but the State Medicaid Manual indicates that a blood lead test result equaling or exceeding 10 µg/dL should be confirmed by a venous sample. As discussed further below, however, reliable and efficient point-of-care capillary tests can now be performed in a primary care provider’s office. As a result, some advocates argue that because the EPSDT benefit covers preventive care and case management when deemed medically necessary by the child’s provider, a provider’s judgment should determine whether a confirmatory venous test is needed.

Definition of Elevated Blood Lead Level

The EPSDT benefit covers preventive care and case management (as well as any other services listed under 42 U.S.C. § 1396d(a)) when a provider determines the services are “necessary … to correct or ameliorate defects and physical and mental illnesses and conditions discovered by screening services, whether or not such services are covered under the State plan.” Thus, any follow-up services listed under § 1396d(a) should be covered if a child’s treating provider determines that the services are medically necessary to ameliorate an elevated BLL. Though the State Medicaid Manual indicates that a BLL at or above 10 µg/dL may trigger follow-up treatment and investigations, this BLL is outdated and does not reflect the CDC’s current reference value of 5 µg/dL. A provider’s judgment (which should be based on current standards of care) should determine the BLL at which case management or other services are needed and provided.

Reporting

State Medicaid agencies are required to annually report EPSDT data to CMS, including the number of lead screening tests performed for Medicaid-enrolled children ages birth to six years old. States may, but are not required to, use and report on the Healthcare Effectiveness Data and Information Set (HEDIS) blood screening measure developed by the National Committee for Quality Assurance (NCQA); the HEDIS measure reflects children two years old who have had at least one blood lead test by their second birthday. Thus, complying with the HEDIS performance measure does not equal compliance with federal Medicaid testing requirements, which as noted call for two tests (at 12 and 24 months of age), not one.

In addition to Medicaid’s lead screening requirements, a number of states have implemented laws requiring either additional targeted screening or universal screening for children at specified ages. This issue brief highlights laws in Ohio and Illinois.

Ohio

Ohio law requires that all children at risk of lead poisoning (as defined by the Ohio Department of Health (ODH)) must receive a blood lead screening test at times determined by ODH rules (which must be consistent with CDC guidelines). ODH rules specify that a child is at risk of lead poisoning and therefore must undergo a lead screening test if the child is under six years of age and meets one of the following criteria:

1. The child is Medicaid eligible under Ohio law.
2. The child lives in a high risk zip code as designated by the ODH director.
3. The child lives in or regularly visits a residential unit, child care facility, or school built before 1950.
4. The child lives in or regularly visits a residential unit (including homes, day care centers, preschools, and homes of relatives or day care providers) built before 1978 that has deteriorated paint or has recent, ongoing, or planned renovation.

5. The child has a sibling or playmate who has, or previously had, lead poisoning.

6. The child is in frequent contact with an adult whose hobbies or work relate to lead.

7. The child lives near an industry known to generate airborne lead dust, such as an active lead smelter or a battery recycling plant.49

A handout summarizing Ohio lead screening requirements, including a list of designated high risk zip codes, is available from the ODH website.50

ODH regulations place responsibility on primary health care providers of children under six years old to: determine whether a child has had a blood lead screening test (and if so, at what age and with what result); if the child has not had a test, determine whether the child is at risk of lead poisoning as defined by the rules; and order a blood lead test if an at-risk child has not previously been tested or the results are not available.51 In addition, the provider must make a good faith effort to obtain results of all blood lead tests performed on an at-risk child.52 Blood lead testing requirements do not apply to a child whose parents object to the test on religious grounds,53 but the objection must be documented in the child’s medical record.54

**Testing Methodology**

ODH regulations state that blood lead screening tests shall be conducted either by venous draw or by capillary test (collected in a capillary tube or on filter paper); however, if a result of 5 µg/dL or greater results from a capillary test, a confirmatory test by venous collection is required as soon as possible but within ninety days.55 Point-of-care testing devices may not be used for confirmatory blood lead tests.56

**Definition of Elevated Blood Lead Level**

ODH rules specify actions which must be taken by the department (or by a designated local board of health) in response to an elevated BLL, with separate requirements applicable to BLLs of at least 5 µg/dL but less than 10 µg/dL, or BLLs of 10 µg/dL or higher.57

**Reporting**

Any clinical laboratory that analyzes blood lead test results for children under 16 years of age and residing in Ohio must report the test results (plus specified demographic and medical data) to the Ohio Department of Health within seven calendar days of obtaining the result.58 The health care provider that requests the blood analysis must provide the necessary personal and medical data to the laboratory to facilitate reporting.59 ODH must then forward any tests indicating the presence of lead in a child under 16 years old to the appropriate local board of health within ten calendar days and must place all blood lead test results on the state’s immunization registry.60

**Ohio Medicaid & CHIP**

All Medicaid-eligible Ohio residents that are under 21 years old are entitled to Ohio’s EPSDT benefit, referred to as “healthchek.”61 Healthchek covers screening services, which include laboratory tests and specifically BLL assessments “appropriate to age and risk factors” as required by CMS.62 Additionally, screening services are to be provided at the frequency prescribed by the Bright Futures Guidelines and at intervals deemed medically necessary to prevent physical or mental illnesses or conditions.63 Accordingly, blood lead tests must be performed at ages 12 and 24 months, and children between three and six years old must be tested if they have not been tested before. Ohio’s CHIP program is provided in combination with its Medicaid program and thus CHIP recipients must be tested as required under the Medicaid EPSDT benefit.64
Illinois

The Illinois Lead Poisoning Prevention Act requires blood lead testing for all children who are six years of age or younger and who are at high risk of lead poisoning either because they reside in a high-risk area or because they meet one or more risk criteria identified by the Illinois Department of Public Health (IDPH). The IDPH has developed a Child Lead Risk Questionnaire outlining lead exposure risk factors; blood lead testing is required if the questionnaire yields one or more responses of “yes” or “don’t know”:

1. The child lives in a high-risk zip code (note that all Chicago zip codes are considered high risk).
2. The child is eligible for Medicaid, Head Start, All Kids, or WIC.
3. The child has a sibling with a blood lead level of 10 µg/dL or higher.
4. The child lives in or regularly visits, or has been exposed during the past year to repairs, repainting or renovations of a home built before 1978.
5. The child is a refugee or adoptee from a foreign country.
6. The child has been to Mexico or to Central or South American or Asian countries where lead exposure may have occurred.
7. The child lives with someone whose job or hobby involves lead.
8. The child has ever lived near a factory where lead is used.

Any child with an elevated screening result from a blood lead test shall receive follow-up testing. In addition, as discussed further below, all Medicaid-enrolled children in Illinois are entitled to screening at the frequency set forth in Medicaid guidelines, namely testing at 12 and 24 months and if a child under age six has not previously been tested.

The Lead Poisoning Prevention Act places responsibility on “any physician licensed to practice medicine in all its branches” and on health care providers who see or treat children six years of age or younger to evaluate and/or test children for lead poisoning as required by law. Licensed, registered, or approved health care facilities (including health departments and health maintenance organizations) that serve children six years old and younger are also required to “take the appropriate steps to ensure” that children are evaluated for risk, tested for lead poisoning, or both, as required by law.

Illinois law further requires that every child care facility or school licensed or approved by the state (including programs operated by public school districts) must require that the parent or legal guardian of a child between the ages of six months through six years provide a health care provider’s statement indicating that the child has been screened or assessed for lead poisoning. In addition, health care providers must evaluate children of any age for lead poisoning in conjunction with mandatory school health examinations if, in the medical judgment of the provider, the child may be at high risk of lead poisoning. IDPH rules provide an exception to lead screening requirements if a child’s parent or guardian objects to the screening on religious grounds.

The IDPH has prepared reference guides for health care providers and for local health departments. Note that the Illinois Lead Poisoning Prevention Act reserves for cities the right to implement local ordinances and regulations pertaining to lead poisoning prevention.

Testing Methodology

Illinois rules define a blood lead test or screen (the terms are used interchangeably) as a test accomplished by venous or capillary methodology. However, the rules require that elevated capillary results (defined as 10 µg/dL or above) must be confirmed by a venous sample.

Definition of Elevated Blood Lead Level

A confirmed BLL is defined as one which is confirmed by venous blood lead test. IDPH rules define “elevated results” as a blood lead test result which is 10 µg/dL or higher.
Note that the City of Chicago Department of Public Health has defined “lead poisoning” as a confirmed BLL of greater than 5 µg/dL.\(^80\)

**Reporting**

Clinical laboratories must report all blood lead test results (plus additional specified information) to the IDPH. Results which verify an elevated BLL must be reported within 48 hours of verification, while negative blood lead test results must be reported within 30 days following the month in which the results were received.\(^81\)

Physicians, health care providers, hospital administrators, and public health officers who have verified information of an elevated BLL must report this information to the IDPH within 48 hours, unless the analysis was performed by the state laboratory or the provider has ascertained that the processing laboratory electronically reports BLLs directly to the IDPH.\(^82\)

**Illinois Medicaid & CHIP**

The Illinois Medicaid program, which includes the “Healthy Kids” (EPSDT) benefit, is operated by the Illinois Department of Health and Family Services (IDHFS). The Illinois CHIP program, All Kids, is a combination program and includes EPSDT services.\(^83\) Accordingly, children enrolled in Illinois Medicaid or All Kids must be tested for lead as required under the Healthy Kids benefit.\(^84\)

In alignment with federal law, IDHFS policy requires that all children enrolled in its Medical Programs be considered at risk of lead poisoning regardless of where they live.\(^85\) Thus, children enrolled in the program must receive a blood lead test at 12 and 24 months old, as required under federal law. If a child three to six years old has not been tested, the child must receive a blood lead test.\(^86\) Lead screening must be conducted in accordance with the Lead Poisoning Prevention Act, and screenings and medical follow up shall be provided in accordance with the IDPH publication, “Guidelines for the Detection and Management of Lead Poisoning for Physicians and Health Care Providers,” which recommends screening on a regular basis for children at high risk of lead exposure.\(^87\)

**CDC Guidance**

The CDC’s Advisory Committee on Childhood Lead Poisoning Prevention (ACCLPP) recommends universal blood lead testing unless state or local public health agencies have developed their own lead screening recommendations based on local lead exposure data.\(^88\) The most recent CDC guidance for creating state or local targeted screening plans was developed in 1997. At that time, CDC recommended universal screening requirements in communities that have either a significant portion of housing stock built before 1950 (≥27%) or 12 percent or higher prevalence of elevated BLLs (≥10 µg/dL)\(^89\) among children between 12 and 36 months old. The 1997 guidance also advised targeted screening for higher risk populations living in communities with overall lower prevalence of elevated BLLs.\(^90\)

The ACCLPP further recommends screening for lead in children arriving in the United States from other countries as well as screening infants born to women exposed to lead during pregnancy or lactation.\(^91\)

**Common Barriers to Screening**

While the U.S. has seen noteworthy increases in the number of children being tested for lead poisoning, an alarming number of children, including those identified as high-risk, are regularly left untreated. A Reuters study found that up to half of children enrolled in Medicaid, despite federally mandated testing at ages one and two, are not tested. The report
indicated that the full scope of under-testing is impossible to gauge given the incomplete data available from state and federal agencies. 92

Several barriers have led to under-testing across states despite screening mandates. First, some physicians may not be aware of (or may disagree with) state and federal testing requirements and the risks associated with even low levels of lead exposure. As a result, physicians may not order needed blood tests and/or may be unaware of or unwilling to provide on-site lead testing. 93 Thus, some states—including Illinois and Ohio—target physician and caregiver awareness as points of intervention in increasing blood lead testing. 94 The CDC likewise recommends physician education on the prevalence of lead poisoning in the provider’s community, unusual sources of lead exposure, public sector services and interventions. 95

Even when a physician is systematically referring young patients for blood lead screening, parents may not follow up on a doctor’s referral for testing or children may miss scheduled appointments. 96 This may result if parents do not identify lead poisoning as a major health concern for their children. 97 A lack of understanding of both the sources of risk as well as the harms once a child is exposed likely contribute to low numbers of testing requests and follow-up. Moreover, even if a parent is provided education on lead poisoning and their child is referred for testing, transportation and scheduling may still pose barriers to follow-up when testing services are not immediately available in the provider’s office. 98 If a confirmatory venous blood test is a prerequisite to obtaining follow-up care, transportation and scheduling barriers may persist even where point-of-care capillary testing is available.

And finally, while not a barrier to screening per se, inconsistent data collection and a lack of dissemination and use of data make it difficult to efficiently solve public health challenges. In particular, a lack of consistent and reliable data makes it difficult to define the scope of a problem, identify appropriate solutions, educate stakeholders, and then accurately evaluate the effectiveness of strategies employed. 99 More information regarding the need for improved data collection can be found under Monitoring and Reporting below.

**Strategies to Improve Childhood Screening Rates**

**Non-Legal Strategies**

While the U.S. has experienced a substantial decrease in lead poisoning over the last decade, lead exposure remains a major public health issue with significant numbers of children experiencing elevated BLLs across the country. Moreover, because lead is still prevalent in the environment and there is no safe level of exposure, primary prevention strategies must be accompanied by vigilant screening to mitigate harmful effects when a child is exposed. States and public health advocates should focus renewed attention on strategies that were effectively employed in past years to increase blood lead testing as well as utilizing current research, technology, and legal tools to ensure that testing remains a priority for state and local health departments, health care providers and parents.

**Parent/Caregiver Education**

Parental education regarding the risks of lead exposure and the need for frequent/regular screening is an important step toward increasing childhood screening rates. The CDC recommends distribution of parent- and group-specific educational materials to help parents not only understand the risks but also the implications of screening results. 100 Educational materials can encourage parents to discuss screening with their child’s health care provider. To improve the reach of educational campaigns, public health efforts could be focused on training community partners such as day care providers, churches, or preschool programs to educate parents on the importance and local availability of lead screening. 101 These partners might also help to assure that educational materials are culturally and linguistically appropriate for the target community.

**Provider Education**
State agencies must also ensure that healthcare providers are receiving up-to-date information on the lead poisoning risk to their patients and the need for screening. Health care providers must understand the important role they play in identifying at-risk children and educating parents on the importance of screening and follow-up. Health care providers (including individual practitioners, hospitals, health plans and health departments) should also be educated on legal requirements pertaining to lead screening and should be aware that many laws place responsibility on providers to assure appropriate screening. A provider’s awareness of his or her legal responsibilities relative to lead screening may facilitate heightened vigilance. The CDC has recommended outreach through pamphlets, grand rounds, and continuing education programs targeted to pediatricians, family practitioners, pediatric and community health nurses, obstetricians, and midwives as an approach to educating providers on this issue.\textsuperscript{102}

\textbf{Health System / Clinic Policies & Procedures}

Strategies for increasing screening rates could also include implementing policies or protocols within a clinic or health system requiring lead screening—or at least an inquiry about lead screening—for all patients under a certain age. By requiring universal screening within a clinic, the issue is less likely to be overlooked or forgotten. Similarly, lead screening reminders could be incorporated into electronic health records, prompting providers to inquire during well-visits about a child’s most recent blood lead test. Finally, lead screening rates could be incorporated into quality assurance and/or improvement activities so that this metric is at the forefront of conversations among health system or clinic staff and leadership. The metric might also be considered when reviewing or evaluating individual providers’ performance, and a system or clinic could consider incentivizing individual providers to improve screening rates.\textsuperscript{103}

\textbf{On-Site / Point-of-Care Screening}

Easing the process of obtaining a blood test may further increase screening rates. Low-income populations most at risk for lead poisoning may experience a lack of transportation or scheduling issues as barriers to obtaining a blood test at an off-site lab. Physicians also cite missed appointments as a reason for low screening rates. Thus, offering lead screening in the provider setting through capillary tests administered via point-of-care screening devices or through on-site labs or phlebotomy may help to bolster screening rates. Point-of-care screening devices are approved by the FDA for use in nontraditional laboratory settings such as physician offices, WIC clinics, and mobile or school clinics, since they do not have to be operated by skilled laboratory personnel.\textsuperscript{104} States may find that offering screening services during other social service visits, such as WIC appointments where finger- or heel-stick tests are already routine, eases time and transportation related barriers to initial testing.\textsuperscript{105} Families may still require assistance with coordinating follow-up venous testing if indicated.

\textbf{Cross-sector Collaboration}

Advocates may find that cross-sector partnerships yield additional opportunities and resources to encourage lead screening, especially when potential partners have their own specific legal obligations related to lead screening. For example, Head Start programs are required to determine a child’s health status upon entry into the program, including obtaining from a health care professional a determination as to whether the child has received age-appropriate primary and preventive health care based on a schedule that incorporates the state’s EPSDT program schedule.\textsuperscript{106} Thus Head Start programs must determine whether a child has been screened for lead in accordance with the EPSDT program requirements. The Head Start program must then assist parents in bringing children up-to-date and/or obtaining follow-up care if needed, and must track provision of health care services to children and assure that they continue to receive age-appropriate services.\textsuperscript{107} Given these requirements, Head Start programs may be interested in partnering with public health programs and health care providers to facilitate access to lead screenings.

Recent amendments to the U.S. Department of Housing and Urban Development’s Lead Safe Housing Rule may similarly provide opportunities for collaboration between public health and public housing agencies.\textsuperscript{108} The Lead Safe Housing Rule requires that if the entity responsible for a federally assisted housing unit is notified that an occupant under age six has an elevated BLL, the entity must complete an environmental investigation of the child’s dwelling unit and common areas serving that unit. If lead-based paint hazards are identified, the entity must undertake appropriate hazard reduction,
control or abatement actions as specified in the law; must notify other building residents of the actions taken; and must conduct lead risk assessments (and appropriate follow-up) for all other federally assisted units within the property in which a child under age six resides.  

The rule further requires Tenant-Based Rental Assistance Programs (e.g., Section 8 programs) to offer address data to and request blood lead data from public health agencies in order to identify homes where environmental investigations are needed. Given these requirements, public health advocates may find public housing agencies (and the public health agencies to which they report) to be important sources of data that should trigger lead screenings.

Additional cross-sector partners may include environmental agencies or public water systems (which could alert public health agencies to environmental or water treatment changes that may create new sources of lead exposure); elementary schools and daycare centers, especially if they are required to confirm that students have been screened for lead (as in Illinois); and WIC clinics which, as noted above, may already conduct capillary blood tests and which in some states may be required to test for lead.

**Legal Strategies**

There are a number of legislative, regulatory and contractual approaches that states may implement to increase childhood lead screening rates. Advocates may also consider litigation as a mechanism for improving enforcement of existing laws.

**Universal Screening Requirements**

Universal screening has been identified as a “best practice” for increasing blood lead testing, in part because targeted approaches may fail if not all lead sources are known. As of January 2017, the Safer Chemicals, Healthy Families coalition identified a universal screening requirement in ten states and the District of Columbia. For example, Massachusetts has implemented regulations requiring that all children in the state be screened for lead at least once between nine and 12 months of age and again between two and three years of age. Children at higher risk of lead exposure must be screened more frequently as specified in the rules. Maryland has similarly implemented a universal screening requirement for children born on or after January 1, 2015, but accomplished the change by updating its targeted screening plan rather than by implementing a universal requirement by statute or regulation. Specifically, in its most recent targeted screening plan, the Maryland Department of Health and Mental Hygiene designated all zip codes and census tracts in the state as “at risk”; thus, all children living in the state are subject to existing blood lead testing requirements.

**Monitoring and Reporting**

No matter the legal screening policy in place, states must assure proper documentation and reporting by health care providers and/or laboratories and must implement a system for monitoring lead screening rates. In the absence of reporting or monitoring, states have no way to determine whether or how often lead testing occurs and therefore cannot take meaningful steps toward improving screening rates (e.g., by enforcing existing laws). In contrast, consistent and timely reporting and careful monitoring may allow state agencies to adjust their policies to incorporate outreach, education, and screening requirements that are most beneficial to the population served and to target remediation efforts to the highest-need areas. In turn, if state agencies are required to report lead screening data to the legislature and to the public, the data may help to bolster screening rates and lead poisoning prevention activities by drawing attention to the issue, increasing political pressure to address it, and ultimately leading to increased funding or improved laws.

Federal agencies should also require state agencies to report lead screening data, not only to facilitate provision of up-to-date best practice information and educational materials for state agencies, health care providers, and parents, but also to develop an accurate picture of lead poisoning in the United States. As noted previously, state Medicaid agencies are required to annually report EPSDT data to CMS, including the number of lead screening tests performed for Medicaid-enrolled children ages birth to six years old. The CDC collects childhood blood lead surveillance data for all children (not
only those enrolled in Medicaid), but its only mechanism for requiring states to report is by including such a provision in funding agreements. The CDC reports that it funds 35 state and local health departments to conduct lead surveillance and therefore cannot require reporting by other states. In the absence of data from all states and because data collection methods vary by state, it is difficult to compare or generalize data across states.

**Medicaid Managed Care Contracting**

According to CMS, over two-thirds of children across the country who are enrolled in Medicaid or CHIP are covered by a managed care organization (MCO). Thus, incorporating lead screening improvement strategies into Medicaid managed care contracts may effectively increase screening among a significant portion of children. In a recent CMS Informational Bulletin addressing blood lead testing, the agency recommended a number of tools for states to engage MCOs in their efforts to improve blood lead screening rates. Suggested methods include:

- Incorporate lead screening requirements into managed care contracts to emphasize the importance of screening and to facilitate state monitoring.
- Require Medicaid managed care plans to use the HEDIS lead screening quality measure developed by the NCQA to evaluate lead screening rates. Though this measure is specific to Medicaid, states could develop a similar quality measure for CHIP managed care programs.
- Using HEDIS or other data, compare health plans’ childhood lead screening performance and require low-performing plans to implement performance improvement projects (PIPs) focused on improving screening rates.
- Encourage managed care plans to provide incentives to their providers to increase screening rates.
- Include childhood lead screening improvement as a mandatory quality metric in the Quality Assessment and Performance Improvement (QAPI) programs that states must require for Medicaid managed care plans.

For an example of how Medicaid managed care contracting can be used to improve screening rates, a report by the New Jersey American Civil Liberties Union (ACLU) describes targeted contract provisions and details the ACLU’s strategy for encouraging the state Medicaid agency to implement them. The National Health Law Program has extensive expertise with Medicaid managed care contracting and is also available to assist with designing and implementing strategic contract provisions.

**Litigation**

Litigation may be used to achieve better enforcement of existing legal screening requirements. Below are several potential approaches as well as resources for further information.

A. Class actions against state Medicaid agencies

Where states have not appropriately implemented the EPSDT benefit—such as by failing to adequately inform patients of the benefit or by failing to provide required services—some advocates have initiated legal actions against state Medicaid agencies. The current Medicaid lead screening, referral and treatment protocol are the result of a nationwide class action case, *Thompson v. Raiford*. There have also been cases filed in individual jurisdictions, including California (*Matthews v. Coye*) and the District of Columbia (*Salazar v. District of Columbia*).

In 1992, advocates in Illinois initiated a successful class action lawsuit against the Illinois Departments of Public Aid and Human Services regarding the state’s provision of EPSDT benefits. The case took over a decade to resolve, but in a 2004 decision, the federal district court for the Northern District of Illinois found that the state was in violation of federal law because it “ha[d] not established a Medicaid program designed to provide all EPSDT services to all Medicaid-enrolled children on a timely basis.” The lawsuit led to a consent decree in which the state agreed to phase in EPSDT program improvements, including by increasing payment rates to providers, offering bonuses to providers for children who received...
Due to the federal requirements discussed above, these program improvements would include steps to improve lead screening and treatment. A Clearinghouse Review article prepared by the attorneys for the case provides additional information on the lawsuit and the resulting consent decree.¹²⁷

For a discussion of more recent EPSDT-related litigation and developments, review Medicaid EPSDT Litigation Trends, by Jane Perkins with the National Health Law Program and the Network for Public Health Law Southeastern Office.¹²⁸ The National Health Law Program frequently leads and/or provides assistance to attorneys challenging states’ implementation of Medicaid requirements.

B. State actions against Medicaid managed care organizations

States could consider initiating breach of contract actions against Medicaid MCOs that fail to provide childhood lead screenings as required by their contracts. Breach of contract actions might be used to enforce either specific contractual provisions relating to lead screening or federal or state laws incorporated into the contract by reference.

As an example of this approach, Missouri’s Attorney General filed a breach of contract action against Prudential Health Care Plan, Inc. in the early 2000s, claiming that the health plan breached its contract with the state (which incorporated federal EPSDT requirements) by conducting lead testing at rates “substantially below 20% of what [was] required.”¹²⁹ An initial lawsuit sought permanent injunctive relief, requested compensation for damages (including reimbursement of capitated payments made for screenings that were not provided and for future medical care, education and related costs to the state resulting from untreated elevated BLLs), and alleged that the health plan violated the Missouri Medicaid Fraud Act by accepting payments for providing services to children despite not providing required lead screening tests.¹³⁰ The court dismissed this initial lawsuit upon finding that the state had failed to comply with notice and opportunity to cure requirements and had failed to plead its fraud claim with sufficient particularity.¹³¹ The state filed an amended complaint soon after, in which the court determined that the state’s damages were limited by the liquidated damages provision in the parties’ contract and found that the state’s request for injunctive relief was moot because the health plan no longer provided Medicaid services for the state.¹³² Though these Missouri lawsuits did not achieve the desired results, the process might offer insights to other states considering similar approaches.

C. Private malpractice actions against health systems and/or health care providers

When children have suffered harm from undetected lead poisoning, individual medical malpractice actions may provide an avenue for legal recourse. For example, several New York lawsuits have alleged medical malpractice associated with a provider’s failure to screen for lead and/or failure to provide anticipatory guidance to a child’s parents regarding lead exposure risks. In some cases plaintiffs have cited the New York Code Rules and Regulations (in addition to expert medical opinions) to establish the standard of care.¹³³ Courts have allowed several cases to survive summary judgment motions, but it seems likely that the cases were ultimately settled.

In addition to obtaining compensation for harm to individual children, the threat of medical malpractice liability may have the added effect of encouraging adherence to higher lead screening standards among health care providers.¹³⁴

Best Practices: Legal & Non-Legal

In January 2017, Safer Chemicals, Healthy Families published a report following a comprehensive examination of state lead testing laws and programs. The author also reviewed state lead screening data and conducted research to identify “best practices” that contributed to success in states with higher screening rates. From this research, she identified the following best practices:
1. Implement universal testing requirements and encourage compliance by educating providers and parents.

2. Combine child health data from various sources to identify untested children and inform their physicians. For example, in some states Medicaid or health department staff send reports to providers indicating which of their patients have not received required lead tests.

3. Cover lead testing costs, whether through Medicaid coverage, free screening programs administered via local health departments, or laws that require insurance plans to cover testing.

4. Increase access to blood lead testing through use of point-of-care devices. Some states provide these devices free to physicians to encourage their use.

5. Require proof of lead testing for school or child care enrollment. Note that states that monitor compliance with school enrollment requirements seem to find greater success in improving screening rates.

6. Require reporting of all lead test results, including those obtained using point-of-care devices.

7. Provide sufficient funding for state lead programs, such as by assessing fees against businesses that contribute to environmental lead contamination. \(^\text{135}\)

For a detailed discussion of each of the practices listed above, review *Children at Risk: Gaps in State Lead Screening Policies*, by Jennifer Dickman with Safer Chemicals, Healthy Families.

Three of these best practices (\#1, 4, and 6 above) were recently implemented in Maryland, offering a glimpse into their potential impact on lead screening rates. First, in early 2015 the Maryland Department of Health encouraged health care providers to use point-of-care (POC) testing by adding whole blood lead testing to the list of tests that qualify for a "Letter of Exception," allowing providers to perform the test without obtaining a permit. \(^\text{136}\) This enables healthcare providers to test children and provide results in the same office visit, simplifying testing and eliminating the need for a second appointment. The Department also added reporting requirements for blood lead test results obtained through POC testing. \(^\text{137}\) In addition, as detailed in the section on Universal Screening Requirements above, Maryland established a universal testing requirement by declaring all ZIP codes in the state to be "at risk" for lead exposure; accordingly, blood lead testing is required for all children at ages 12 months and 24 months, regardless of where they live. This policy change took effect on March 28, 2016 and included a surveillance requirement for ongoing data collection and evaluation. \(^\text{138}\) Following implementation of all of these changes, in calendar year 2016 Maryland saw a 12.2% increase in the percentage of children tested for lead at ages one and two years old (as compared to average testing rates between 2010-2015). \(^\text{139}\) Despite the increase in testing rates, the number of children identified with elevated BLLs dropped between 2015 and 2016. \(^\text{140}\) In addition, the number of healthcare providers using POC testing for lead increased by over 42 percent in calendar year 2016. \(^\text{141}\)

**Conclusion**

There is no safe level of lead exposure for children; indeed, even low levels of lead can cause significant harm to children’s cognitive development. Nevertheless, lead remains a relatively common substance in the environment. Primary prevention efforts must be emphasized and prioritized to provide maximum protection for children. But until lead is eliminated from the environment, blood lead testing is crucial both to prevent further exposure and to mitigate harmful health consequences. Child health advocates can play an important role in assuring appropriate blood lead testing through a combination of non-legal and legal strategies. Key non-legal strategies include educating health care providers and parents about the harms of lead exposure, current standards of care, and legal screening requirements, and promoting use of on-site testing to reduce transportation and scheduling barriers. Important legal strategies include advocating for universal screening requirements and improved reporting, as well as enforcing existing state law and Medicaid requirements through Medicaid contracting as well as through individual or impact litigation.
SUPPORTERS

The Network for Public Health Law is a national initiative of the Robert Wood Johnson Foundation. The Network provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document do not constitute legal advice or representation. For legal advice, please consult specific legal counsel.

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2 Id.
4 Elevated blood levels are those above 5 micrograms per deciliter (µg/dL). Lead, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/nceh/lead/ (last reviewed Feb. 9, 2017).
6 Id.
12 40 C.F.R. §§ 141.51(b).


See Basic Information about Lead in Drinking Water, U.S. ENVTL. PROT. AGENCY (last updated on Aug. 21, 2017), https://www.epa.gov/ground-water-and-drinking-water/basic-information-about-lead-drinking-water ("EPA estimates that drinking water can make up 20 percent or more of a person’s total exposure to lead.").


Id.; Report of the Advisory Committee on Childhood Lead Poisoning Prevention: Low Level Lead Exposure Harms Children: A Renewed Call for Primary Prevention, CTRS. FOR DISEASE CONTROL AND PREVENTION 25 (Jan. 4, 2012), available at https://www.cdc.gov/nceh/lead/acclpp/final_document_030712.pdf [hereinafter CDC ACCLPP Recommendations]. The CDC has observed that “stringent precautions” such as rigorous hand washing can minimize the risk of error and, for surveillance purposes, defines a confirmed elevated blood lead level as one which results from a single venous blood specimen or from two capillary blood specimens drawn within 12 weeks of each other. Id.

AAP: Detection of Lead Poisoning, supra note 20.


See 42 U.S.C. § 1396d(r)(5); 1396c(a).


See 42 CFR § 457.70. See also CMCS Informational Bulletin: Coverage of Blood Lead Testing, supra note 27 at 3.

42 CFR §§ 457.410(b); 457.520.

42 CFR § 457.10.

42 CFR § 457.520.


See id.

Access To Health Screening Services (July 2001); Office of Inspector General, U.S. Dep’t of Health and Human Services, Medicaid Managed Care and EPSDT (May 1997)).


42 U.S.C. § 1396d(r)(5). See also § 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B).

43 U.S.C. § 1396d(r)(5). See also § 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B).


49 Ohio Admin. Code 3701-30-01(D).


52 Ohio Admin. Code Ann. 3701-30-02(D).


55 Ohio Admin. Code 3701-30-03.

56 Ohio Admin. Code 3701-30-03(C).


58 Ohio Admin. Code 3701-30-05(A), (C). See Ohio Admin. Code 3701-32-14 for rules applicable to reporting blood lead test results for persons 16 years or older.

59 Ohio Admin. Code 3701-30-05(B).

60 Ohio Admin. Code 3701-30-05(D), (E).


68 410 Ill. Comp. Stat. § 45/6.2(a).

69 410 Ill. Comp. Stat. § 45/6.2(b).

70 410 Ill. Comp. Stat. § 45/7.1 (requirement applies to children between one and seven years old); 77 Ill. Admin. Code 845.55 (d) (requirement applies to children between six months through six years old). See also Ill. Admin. Code 665.140(f)(1), the Child and Student Health Examination and Immunization Code, noting that lead screening is a required component of a health examination for children between one and seven years of age before entering a day care or school facility or program. Note also that child care facilities participating in the Illinois Child Care Assistance Program (CCAP) must annually send or deliver a lead poisoning informational pamphlet to the parents or guardians of children enrolled in the program. 410 Ill. Comp. Stat. § 45/7.1.

410 Ill. Comp. Stat. § 45/6.2(c); 77 Ill. Adm. Code 665.140(f)(2). Health care providers may assess lead exposure for children seven years and older in accordance with the Lead Risk Assessment Questionnaire. 77 Ill. Admin. Code 845.55(c).

77 Ill. Adm. Code 845.55(e).


76 Ill. Admin. Code 845.20 (definition of “blood lead test”).


78 Ill. Admin. Code 845.20 (definition of “confirmed blood lead level”).

79 Ill. Admin. Code 845.20 (definition of “elevated results”).
Ill. Admin. Code 140.485(d)(7) (Medicaid); 89 Ill. Admin. Code 125.300 (requiring that covered healthcare services under CHIP shall include those covered by the Healthy Kids [EPSDT] program).


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CDC ACCLPP Recommendations, supra note 21, at 23-24.

Note that until 2012, the CDC deemed blood lead levels at or above 10 mg/dL as the “level of concern.” The CDC recently renamed this value the “reference value” in recognition that there is no safe level of lead exposure, and lowered the reference value to 5 mg/dL. Centers for Disease Control & Prevention, CDC Response to Advisory Committee on Childhood Lead Poisoning Prevention Recommendations in “Low Level Lead Exposure Harms Children: A Renewed Call of Primary Prevention” (May 13, 2012; updated June 7, 2012), available at https://www.cdc.gov/nceh/lead/acclpp/cdc_response_lead_exposure_recs.pdf.

CDC ACCLPP Recommendations, supra note 21, at 23-24.


See, e.g., Keeshan et al., supra note 93.


See, e.g., Barbara J. Polivka & Mary Margaret Gottesman, Parental Perceptions of Barriers to Blood Lead Testing, J. PEDIATRIC HEALTH CARE 1, at 5 (May/June 2005), available at https://pdfs.semanticscholar.org/637f/ec12ce05e26ef840d89c18cde3e75b726e34.pdf.


See, e.g., ACLU, Preventing Childhood Lead Poisoning in New Jersey, supra note 93, at 9–10.

Centers for Disease Control & Prevention, Preventing Lead Poisoning in Young Children, supra note 95 at chapter 9.

See, e.g., Wisconsin Childhood Lead Poisoning Prevention Program, supra note 94, at 39.


Polivka & Gottesman, supra note 98.

45 C.F.R. § 1304.20(a).

45 C.F.R. § 1304.20(a).
109 24 C.F.R. §§ 35.325, 35.730, 35.830, 35.1130, 35.1225.
110 24 C.F.R. § 35.1225(g).
113 Id. at 19.
114 105 CMR 460.050(C).
115 105 CMR 460.050(C), (D).
118 ACLU, Preventing Childhood Lead Poisoning in New Jersey, supra note 93, at 6 (describing implications of New Jersey states agencies’ failure to monitor lead screening rates, test results, or responsive activities).
122 Id.
123 Id.
129 Id.
130 Id.
132 Id.
133 Id.
137 Dickman, supra note 112, at 30-33.
139 Id.
140 Id. at 19.
141 Id. at 2.
142 Id. at 3.