Assessing Child Lead Poisoning Case Ascertainment in the US, 1999–2010

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abstract

OBJECTIVES: To compare prevalence estimates for blood lead level ≥10.0 μg/dL (elevated blood lead level [EBLL]) with numbers reported to the Centers for Disease Control and Prevention (CDC) for children 12 months to 5 years of age from 1999 to 2010 on a state-by-state basis.

METHODS: State-specific prevalence estimates were generated based on the continuous NHANES according to newly available statistical protocols. Counts of case reports were based on the 39 states (including the District of Columbia) reporting to the CDC Childhood Lead Poisoning Prevention Program during the study period. Analyses were conducted both including and excluding states and years of nonreporting to the CDC.

RESULTS: Approximately 1.2 million cases of EBLL are believed to have occurred in this period, but 607 000 (50%) were reported to the CDC. Including only states and years for which reporting was complete, the reporting rate was 64%. Pediatric care providers in 23 of 39 reporting states identified fewer than half of their children with EBLL. Although the greatest numbers of reported cases were from the Northeast and Midwest, the greatest numbers based on prevalence estimates occurred in the South. In southern and western states engaged in reporting, roughly 3 times as many children with EBLL were missed than were diagnosed.

CONCLUSIONS: Based on the best available estimates, undertesting of blood lead levels by pediatric care providers appears to be endemic in many states.

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Dr Roberts conceptualized and designed the study, conducted the data analyses, and drafted the initial manuscript; Mr Madrigal conceptualized and researched the policy context and framework for the analysis and reviewed and revised the manuscript; Ms Valle acquired and processed reporting data from the Centers for Disease Control and reviewed and revised the manuscript; Ms King and Ms Kite developed the policy context and framework for the analysis and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

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WHAT'S KNOWN ON THIS SUBJECT: There has long been concern that lead poisoning among many children goes undetected, but only now are researchers able to conduct state-by-state comparisons.

WHAT THIS STUDY ADDS: During the study period, the greatest numbers of children with blood lead levels ≥10.0 μg/dL lived in the South. In 23 of the 39 states examined, the majority of children with these levels went undiagnosed and untreated.

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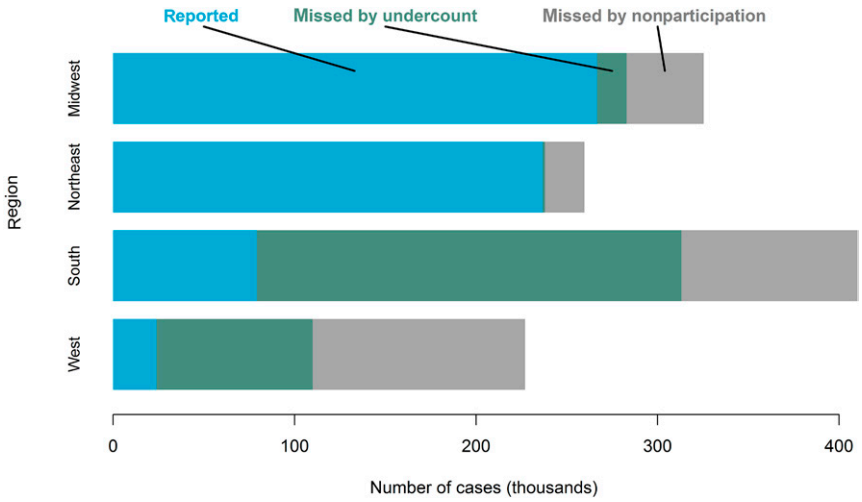

FIGURE 1
Total predicted numbers of children aged 12 months to 5 years with EBLL in 1999 to 2010, by reporting status and region.

In the United States, practices related to screening and testing for elevated blood lead levels (EBLLs) vary widely. American Academy of Pediatrics guidelines[1–3] encourage reliance on screening procedures formulated at the state and local levels to determine who should be tested, but these recommendations are often difficult for clinicians to access and commonly defer to practitioners' individual evaluations of EBLL risk in the communities they serve, a task for which few are equipped.[4] Laws requiring beneficiaries of Medicaid and the Special Supplemental Nutrition Program for Women, Infants, and Children to receive testing are often unenforced,[5] and only 4 states recommend that schools require proof of testing for kindergarten or prekindergarten attendance.[4] For most children, therefore, clinician discretion is the sole determinant of how many and which children are tested for EBLL.

Over the past 2 decades, many states have reported counts of children with EBLL to the Centers for Disease Control and Prevention (CDC) Childhood Lead Poisoning Prevention Program (CLPPP), but because of this variability in screening practices, how these counts relate to EBLL prevalence is impossible to know. Ideally, these counts could be compared with estimated numbers of children believed to have EBLL in each state, revealing whether efforts at case ascertainment by clinicians are indeed adequate. Because independent state-level estimates of EBLL prevalence have not existed, however, this fundamental question could not be addressed.

However, new advances in epidemiology and statistics[6] have made estimates of EBLL prevalence available for each of the 50 states and the District of Columbia for the period 1999 to 2010. For first time, we can compare the numbers of reported cases with those expected on a state-by-state basis, enabling us to quantify the adequacy of state efforts with implications for pediatric practice.

METHODS

Importance of EBLL Detection

Lead is a known neurotoxicant for which no safe level of exposure has been identified.[7] Children aged 1 to 5 years are considered to be at highest risk for exposure (because of their characteristic hand-to-mouth activity) and its ill effects (because of their complex and rapid neurodevelopment).[8] Interventions prompted by the finding of EBLL among patients, including housing and other environmental remediation, have proven efficacy for mitigating lead's toxic effects.[9] Absent testing, however, patients are left to experience the sequelae of continued exposure in their home environments, most notably cognitive and attention deficits and increased impulsivity[10,11] but potentially including insults to the autonomic,[12] renal,[13] and endocrine[14,15] systems.

How EBLL Surveillance Works in the United States

Most states require that blood lead level (BLL) testing results be reported to their public health agencies, although many only require reporting for results over a certain threshold (ranging from 5 to 25 μg/dL).[4] During the period 1999 to 2010, 39 states (including the District of Columbia) participated in the CDC CLPPP reporting program, although participation was intermittent for 18 of these states. In participating, states standardized their definitions of EBLL (eg, a fingerstick sample subsequently verified by a venous sample if over a certain threshold) and submitted numbers of children tested and numbers with results exceeding specific thresholds to the CDC. For this period, the reporting threshold was 10 μg/dL, and subsequently it was lowered to 5 μg/dL. Although not all states have participated in reporting at any given time, these data are the sole source of standardized EBLL case ascertainment numbers for the United States. They demonstrate that the greatest numbers of children for whom EBLL is detected reside in northeastern and midwestern states, with far fewer cases ascertained in the South and West (Fig 1, blue bars).

Comparisons of Case Counts and Prevalence Estimates

We seek to quantify the adequacy of case ascertainment of EBLL among children 12 months to 5 years of age by comparing reported counts with those predicted based on prevalence estimates generated through the application of new statistical methods to the NHANES. Although such a comparison is intuitively valid, there are reasons why these numbers might not agree even if a state had 100% case ascertainment; we posit that these reasons are important enough for the interpretation of the findings below to warrant discussion up front.

The first reason is that, to the extent that NHANES and putatively complete case counts can both be considered sources of epidemiologic data, they represent 2 different study designs. The former is a cross-sectional study of a representative population, the gold standard for determining prevalence and covariates for any disease. In contrast, the latter can be thought of as a rolling enrollment study in which children are permitted to be tested more or less than once per year. Whereas NHANES participants undergo a single venipuncture, clinic patients often undergo fingerstick sampling followed by confirmation with a venous sample after a variable period of time. Therefore, results based on the latter efforts are subject to regression toward the mean and seasonal fluctuations in EBLL prevalence.[16,17]

The second reason is that our prevalence estimates (and therefore the projected counts derived from them) are based on a statistical model. Therefore, given the mix of demographic and housing characteristics in any particular state, we are calculating expected numbers of EBLL cases; the observed number in any given state is understood to be log-normally distributed above and below its expected number. Although nationwide over the entire study period these observed and expected numbers should be very similar, any given state may have case counts higher or lower than projected even under the assumption of perfect case ascertainment. Because we expect extra-Poisson variation among states, standard confidence intervals do not reflect the degree of disagreement that might be expected from random chance.

However, comparison of case counts with prevalence estimates can reveal portions of the United States for which EBLL ascertainment is dramatically lower than expected based on the best available epidemiologic tools. In light of the serious consequences of untreated EBLL for the entire life course, these discrepancies indicate a need for more aggressive testing until state-specific, population-based studies can be conducted that prove previous case ascertainment efforts to be adequate.

CDC Reporting Data

Tallies for state reports of EBLL for each year were obtained directly from the CDC Childhood Lead Poisoning Prevention and Healthy Housing program in June 2016. Some states submitted data for years that were known to be incomplete, either because they were labeled as such by CDC CLPPP or because totals were orders of magnitude smaller than those for other years. For clarity, the present analysis classifies such states as nonreporting during those years.

Model for Prediction of EBLL Prevalence

NHANES has been conducted on a continuous basis since 1999, with data releases occurring at 2-year intervals.[18] Because NHANES is designed to be representative of the entire noninstitutionalized US population, direct subsetting of these data cannot be undertaken to produce state-level prevalence estimates. Instead, researchers may fit multivariate models predicting disease rates based on each state's demographic data; use of these data as model inputs then yields prevalence estimates specific to each state.

To be valid, any such model must include covariates known to be predictive of the disease in question; for EBLL, these include region of the country, race or ethnicity, poverty status, and residence in housing built before the 1978 ban on lead-based paint in the United States. More than a third of NHANES records describing children aged 1 to 5 years are missing this last variable, however, which has precluded the generation of models predicting EBLL prevalence until recently.

To summarize briefly, Roberts and English[6] formulated a *t*-distributed Heckman selection model[19,20] applicable to the case of multiple missing-not-at-random variables in the context of the complex survey design of NHANES, thereby accounting for potential bias in the missing data and enabling the valid estimation of a model predicting EBLL. National-level predictions from the model match well with those arrived at through conventional analyses of NHANES, although the former tend to be slightly lower than the latter. The authors therefore encourage researchers to consider estimates based on their model as conservative, potentially leading to slight underestimations of EBLL prevalence.

Model Inputs

The Roberts and English model is based on NHANES participants aged 12 months through 5 years. Model inputs must therefore be specific to this age stratum, which precludes the use of pretabulated census data for this purpose. Following those researchers, we use microdata from the American Community Survey[21] to generate the inputs described

above for each state and the District of Columbia during the study period. For completeness, we reproduce the coefficients to which these inputs are applied in Table 1. Because NHANES is released at 2-year intervals, prevalence estimates for off-years are calculated via linear interpolation.

Analysis

Because 10 μg/dL was considered the level of concern during the study period, we define EBLL cases as children with BLL greater than or equal to this number.

To depict case ascertainment at the regional level, we begin by calculating the total numbers of children with EBLL we believe to have occurred during 1999 to 2010 based on the projected prevalence for each state. For each year y in state s, we let $\hat{P}_{y,s}$ be the projected prevalence and $N_{y,s}$ be the population of children aged 12 months through 5 years. The expected number of cases is simply $Exp_{y,s} = \hat{P}_{y,s} N_{y,s}$. Each $Exp_{y,s}$ is apportioned by whether y was a year that state s participated in reporting, and (if so) the fraction of the region's sum of all expected cases accounted for in the totals reported to the CDC CLPPP.

For state-level analysis, we formulate an outcome variable θ_s, the cumulative ratio of successful case ascertainment for the years state s participated in reporting. Letting $Obs_{y,s}$ be the number of cases reported and φ be the set of pairs $\{(y,s)\}$ for which reporting to the CDC CLPPP occurred, we specify

$$\theta_s = \frac{\sum_{(y,s)\in\varphi} Obs_{y,s}}{\sum_{(y,s)\in\varphi} Exp_{y,s}}$$

θ_s is therefore a reflection of the successful case ascertainment by clinicians that avoids penalizing those in states that did not participate in reporting during specific years of the study period. Intuitively θ_s can be thought of as an ascertainment success rate ranging from 0% to 100%, with the provisos mentioned above that some of its values may exceed 100%, and some states with perfect case ascertainment may have values of <100%.

TABLE 1 Posterior Distributions for Parameters Predicting BLL ≥10.0 μg/dL, Expressed as Odds (Intercept) and Odds Ratios (All Others), From Roberts and English[6]

Parameter	Mean (95% Credible Interval)
Intercept	0.002 (0.001–0.004)
Race or ethnicity	
Non-Hispanic white and other	1.00
Non-Hispanic black	2.71 (1.77–4.19)
Hispanic	0.46 (0.23–0.92)
Year housing built	
Post-1978	1.00
Pre-1978	3.63 (1.78–8.82)
Household poverty status	
Not in poverty	1.00
In poverty	1.81 (1.16–2.85)
Time (per 2-y cycle, centered at 0)	0.83 (0.73–0.94)
Region of residence	
Residence in Northeast	1.00
Residence in Midwest	1.01 (0.80–1.28)
Residence in South	0.94 (0.82–1.06)
Residence in West	0.95 (0.82–1.12)

RESULTS

About 1.2 million children are estimated to have had EBLL during the period 1999 to 2010. Of these, roughly half (606 709) were reported to the CDC. Of the remainder, ~45% (278 299) occurred in years during which the child's state was not reporting to the CDC, and 55% (337 405) were not reported because of incomplete case ascertainment in states engaged in reporting efforts.

Region-Level Ascertainment

Region-level ascertainment is depicted in Fig 1. The length of each bar is the projected number of children having EBLL during the study period, and the colors reflect the reporting categories discussed above. Although the greatest number of children reported as having EBLL occurred in the Midwest and Northeast, the greatest number of cases occurred in the South. Although the smallest number of cases occurred in the West, this was also the region with the greatest proportion of missed cases (89%) due both to ineffective ascertainment and to nonparticipation in the CDC CLPPP. Excluding nonparticipating states and years, proportions of EBLL cases that were reported in the Northeast, Midwest, South, and West were 99.5%, 94.3%, 25.3%, and 21.8%, respectively.

State-Level Ascertainment

Ascertainment ratios θ_s are listed in Table 2 and displayed graphically in Fig 2. As expected, several states have ratios slightly below or substantially exceeding 1.0, which may be interpreted as evidence that clinicians in these states captured nearly all the EBLL cases that occurred (or at least a lack of evidence suggesting otherwise). Most disconcerting is the finding that the summary θ value is well below this number at 0.64; because the summary value can be considered similar to a population mean, it suggests that a portion of the population of states is associated with substantial underdetection.

The majority of the states (23) reported fewer than half of the expected number of EBLL cases, and 11 reported <20%. Although for statistical reasons we expect some states to have values substantially <1.0, the positive skewness of this distribution (ie, the large number of states with θ_s<0.5) is striking. In the absence of epidemiologic data demonstrating that the prevalence of EBLL in any of these states is lower than estimated, underreporting (and therefore undertesting) should be considered potentially endemic in these states.

Although selected characteristics of participating states' guidelines for clinicians are displayed in the right-hand columns of Table 2, no configuration of guidelines appears

TABLE 2 Years Reporting to CDC CLPPP, Predicted Numbers of Cases of BLL ≥10.0 μg/dL, Numbers Reported, Ascertainment Success Ratio, and Selected Characteristics of Testing Guidelines, by State and District of Columbia, 1999–2010

			Predicted BLL ≥10.0 μg/dL			Selected Characteristics of State Testing Guidelines[a]		
State[b]	Years Reporting (Maximum 12)	2010 Prevalence (per 1000)	No. Cases, (Reporting Years Only, Thousands)	No. Reported (Thousands)	Ascertainment Success Ratio (θ_s)	All Children at Defined Ages	Children Who Participate in Publicly Supported Programs at Defined Ages	Children Entering Public School at Defined Ages
All participating states			944.1	606.7	0.64			
Arizona	12	1.6	15.2	2.2	0.14	No	Yes	No
California	7	2.1	53.4	19.9	0.37	No	Yes	No
Colorado	3	2.0	5.6	0.3	0.06	No	Yes	No
Connecticut	12	3.2	14.6	17.7	1.21	Yes	No	No
Delaware	11	2.8	3.0	1.4	0.47	Yes	Yes	Yes
District of Columbia	11	6.8	4.9	1.8	0.37	Yes	Yes	No
Florida	12	2.3	50.5	7.3	0.15	No	Yes	No
Georgia	12	2.7	36.6	3.7	0.10	No	Yes	No
Illinois	5	3.4	37.5	80.5	2.15	No	Yes	No
Indiana	12	3.2	29.7	7.1	0.24	Yes	No	No
Iowa	12	3.4	14.2	11.0	0.77	Yes	No	Yes
Kansas	12	3.0	12.0	3.5	0.29	Yes	Yes	No
Kentucky	10	2.8	12.2	1.6	0.13	No	Yes	No
Louisiana	12	3.8	28.1	7.2	0.26	Yes	No	No
Maine	12	2.8	4.6	3.1	0.67	No	Yes	No
Maryland	11	3.3	22.7	17.0	0.75	No	Yes	Yes
Massachusetts	12	3.4	28.7	30.0	1.04	Yes	No	Yes
Michigan	12	3.8	52.9	40.7	0.77	No	Yes	No
Minnesota	12	2.9	21.2	8.5	0.40	No	Yes	No
Mississippi	9	3.8	10.8	3.0	0.28	No	Yes	No
Missouri	12	3.4	26.9	26.9	1.00	No	Yes	No
Nevada	5	1.6	1.8	0.1	0.05	No	No	No
New Hampshire	12	2.7	4.0	4.2	1.04	No	Yes	No
New Jersey	11	3.2	34.3	25.4	0.74	No	No	No
New Mexico	3	1.6	1.8	0.1	0.05	No	No	No
New York	11	3.8	97.9	88.8	0.91	Yes	No	No
North Carolina	11	2.4	29.3	7.4	0.25	Yes	Yes	No
Ohio	12	3.9	63.6	59.1	0.93	No	Yes	No
Oklahoma	12	2.8	13.4	1.9	0.14	No	Yes	No
Oregon	12	2.4	12.4	0.9	0.08	No	No	No
Pennsylvania	10	3.7	47.7	51.6	1.08	Yes	Yes	No
Rhode Island	12	3.4	3.9	14.6	3.73	Yes	No	No
Tennessee	10	2.8	20.3	3.2	0.16	Yes	No	No
Texas	8	1.8	47.2	16.2	0.34	No	Yes	No
Vermont	12	3.4	2.2	1.5	0.68	Yes	No	No
Virginia	12	2.7	28.3	5.9	0.21	No	Yes	No
Washington	11	2.3	19.9	0.4	0.02	No	No	No
West Virginia	11	2.9	5.8	1.5	0.25	No	Yes	No
Wisconsin	12	3.3	25.1	29.7	1.19	No	Yes	No

[a] State characteristics for 2015 from Sykes,[4] District of Columbia for 2011–2014 from District of Columbia Department of the Environment.[22]

[b] States not participating in reporting to the CDC during these years included Alabama, Alaska, Arkansas, Hawaii, Idaho, Montana, Nebraska, North Dakota, South Carolina, South Dakota, Utah, and Wyoming.

to be associated with consistently high case ascertainment. This finding conforms to our impression that clinicians are often unaware of the guidelines, and if they are aware, then lack of enforcement undermines any effect they might have on clinician behavior.

DISCUSSION

We used prevalence estimates among the 50 states plus District of Columbia to calculate the expected number of children with EBLL over the period 1999 to 2012 and compared these with the numbers reported to the CDC. Among participating states during years with complete reporting, 36% of children with EBLL (equal to 337 405 cases) were not documented. If we extend this ascertainment rate to include nonparticipating states, then the number of nondocumented cases becomes 437 593. Although we find

no evidence of underascertainment in a number of states, the majority appear to successfully identify fewer than half of their children with EBLL. Because our prevalence projections may be low, these estimates of nonascertained children may be considered conservative.

After the removal of lead from gasoline and residential paint products, the prevalence of EBLL among children declined dramatically[23]; consistent with this trend, state and federal regulations and guidelines have become less demanding over time. Whereas in 1991 CDC guidelines recommended universal screening, in 1997 the CDC formally began deferring to individual states to generate their own guidelines, ideally including the testing of all Medicaid beneficiaries, and suggested universal testing only in the absence of a state-level plan.[24] Beginning in 2009, the recommendation of universal testing of Medicaid beneficiaries was itself softened[25] to one of questionnaire-based screening[26] for the need for testing. Federal reasoning throughout this time was that states and localities would be able to formulate "data-driven policies" regarding EBLL prevalence in their jurisdictions, although population-based prevalence studies for these jurisdictions were neither funded nor required.

Despite this relaxation of standards, concerns that only a fraction of children with EBLL were being detected were ongoing during this period. The US General Accounting Office determined in 1999 that only 11% of Medicaid beneficiaries were tested,[5] and as of 2001 only 17% of the estimated numbers of cases nationally were diagnosed by clinicians.[27] Even then ascertainment success varied from state to state, with many states reporting disproportionately few cases relative to objective measures such as the age of their housing

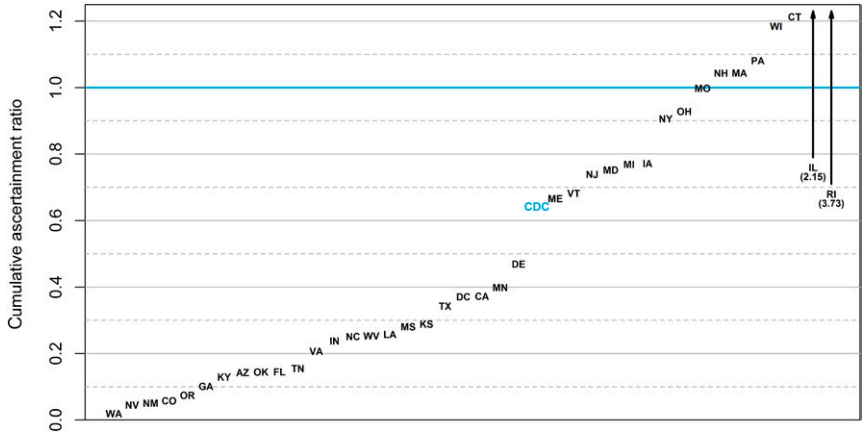

FIGURE 2
Ratios of reported-to-predicted EBLL case counts among states participating in CDC CLPPP reporting, 1999 to 2010. Overall ratio ("CDC") indicated in blue.

stock.[27] Numbers of tests generally increased through 2010, which along with our conservative prevalence estimates may account for the high ascertainment ratio of 64% reported here.

Particularly in nonreporting states, some of the children with EBLL missing from the CDC tally may have been diagnosed and received case management services (see McClure et al[28] for an analysis of BLL testing that includes some of these states). Conversely, however, many that were diagnosed and reported received no environmental mitigation services. Protocols for monitoring and service provision for children with EBLL vary by state and locality, including thresholds for case management and types of services eligible for Medicaid reimbursement.[29] The budget for the CDC Childhood Lead Poisoning and Healthy Homes program was itself reduced from $29 million to $2 million in 2012, leading to a loss of 57% of state positions responsible for primary prevention, environmental assessments, enforcements of lead-safe building laws, and outreach and education to lay and professional audiences, as well as for surveillance itself.[30]

Since the close of the study period in 2010, the public health community's ability to rely on NHANES for EBLL surveillance has eroded in 2 respects. First, ostensibly because of the history of item nonresponse, NCHS began omitting age of housing from NHANES questionnaires after this time. Also, temporal declines in the prevalence of EBLL mean that the NHANES sample size (~630 children of the appropriate age per year) is inadequate to detect meaningful numbers of cases in a survey cycle. As a result, NHANES data more recent than 2010 are not amenable to the type of analysis presented here, and clinician reporting is becoming our sole source of population-level information with which to steer public health policy and action.

At the same time, EBLL remains an ongoing threat to the health of the nation's children. Although events in Flint, Michigan focused the attention of the American public,[31] subsequent analyses have demonstrated that thousands of communities throughout the country are known to have higher prevalences of EBLL based on the partial reporting that does occur.[32] Furthermore, the ongoing phenomena of race- and class-based segregation and our aging infrastructure dictate that we have no guarantee that EBLL prevalence will fall uniformly over time or equally among all communities. Many of the children

enumerated in the current study are currently school age and need additional resources for their education; in all, child EBLL costs the United States ~$50 billion in lost economic productivity annually.[33]

American Academy of Pediatrics policy, including that expressed in Healthy Futures protocols for well child assessments, explicitly defers to state and local health departments to decide when children should undergo BLL testing.[1–3] This policy is based on 2 assumptions, however: that well-resourced public health agencies will communicate effectively with providers, enabling them to make data-directed decisions about when to test for EBLL, and that statutory requirements for testing would be accompanied by mechanisms and resources for enforcement. Both of these assumptions have proven to be false, with the effect that large numbers of children with EBLL (indeed, the majority of these children in many parts of the country) have been missed by clinicians.

Departments of public health should reach out to providers and make sure their guidelines are accessible and feasible given the typical provider's skill set and time availability. Ideally they should conduct population-based EBLL prevalence studies that would produce more reliable estimates than our model-based ones and enable allocations of resources to assist communities most in need.

Clinicians should not wait for their state and local agencies to be granted sufficient resources to act, however; those in states with poor ascertainment need to begin testing more aggressively. They also need to inform themselves about how to counsel parents in the event of a positive finding. This information includes knowledge of resources set aside by states and localities for environmental remediation and legal protections against retaliatory rent increases and evictions by landlords.[34]

CONCLUSIONS

We compared observed counts of EBLL cases among children 12 months to 5 years of age reported to the CDC during 1999 to 2010 with expected counts based on the NHANES population-based surveys. During this period, 1 in 3 children believed to have EBLL in participating states went unreported. Although the majority of reported cases resided in the Northeast and Midwest, the largest numbers of children with EBLL resided in the South, and pronounced underreporting took place in the South and West. We also identified states for which underascertainment of EBLL cases appears to have been endemic during this period. Unless population-based studies can demonstrate EBLL prevalence to be lower than our estimates suggest in these states, clinicians there are urged to pursue more aggressive testing.

ABBREVIATIONS

BLL: blood lead level
CDC: Centers for Disease Control and Prevention
CLPPP: Childhood Lead Poisoning Prevention Program
EBLL: elevated blood lead level

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