

January 1999

# LEAD POISONING

## Federal Health Care Programs Are Not Effectively Reaching At-Risk Children



  
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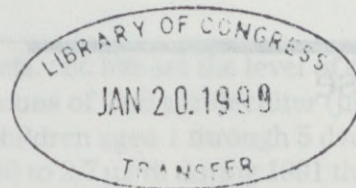
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January 15, 1999

The Honorable Henry A. Waxman  
Ranking Minority Member  
Committee on Government Reform  
House of Representatives



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Dear Mr. Waxman:

This report responds to your request that we review federal activities for ensuring that at-risk children receive screening and treatment for lead poisoning. In particular, this report addresses the risk of lead poisoning faced by children served by federal health care programs, the extent to which children served by these programs have been screened for this condition, reasons why screenings may not be occurring, and problems faced by federal health care programs in ensuring that children who have been identified as having harmful lead levels in their blood receive timely follow-up treatment and other services.

As arranged with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after the date of this letter. We will then send a copy to the Secretary of Health and Human Services and others who are interested.

Please contact me at (202) 512-7119 if you or your staff have any questions. Other GAO contacts and major contributors to this report are listed in appendix IX.

Sincerely,

Bernice Steinhardt  
Director, Health Services Quality  
and Public Health Issues



# Executive Summary

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## Purpose

Lead poisoning, a preventable condition, is one of the most serious environmental health threats to children in the United States. Among young children, elevated blood lead levels impair mental and physical development. Because most children display no obvious symptoms, the best way to detect the condition is through a screening blood test. After administering such tests to a representative sample of children aged 1 through 5 as part of a nationwide health survey conducted between 1991 and 1994, the Department of Health and Human Services (HHS) estimated in 1997 that about 890,000, or 4.4 percent, of the children in that age group had harmful levels of lead in their blood.

Children in low-income families who live in older housing with deteriorating lead-based paint are at high risk for lead poisoning. The federal government, as a major source of health care funding for the low-income population, has set policies that young children who receive federally supported health care should receive lead screening services. The extent to which federal health care programs are actually screening and providing adequate treatment services to children found with harmful blood lead levels, however, remains unknown. Consequently, the ranking minority member of the House Committee on Government Reform asked GAO to address (1) the risk of lead poisoning faced by young children served by federal health care programs, (2) the extent to which children served by these programs have been screened for this condition, (3) key reasons why screenings may not be occurring, and (4) problems that federal health care programs face in ensuring that children who have harmful lead levels in their blood receive timely follow-up treatment and other services.

## Background

Until recently, the Centers for Disease Control and Prevention (CDC), the HHS agency recommending U.S. policy for lead screening and treatment, has stated that virtually all children ages 1 through 5 should receive a blood lead test. However, national health surveys that CDC conducts periodically have shown a marked decline in the prevalence of elevated blood lead levels in recent years, attributed primarily to the regulatory ban on lead in gasoline and lead-soldered food cans. The surveys, most recently conducted from 1991 through 1994, involve physical examinations and interviews for a representative sample of virtually all age groups across the country. The physical exams include a blood lead test, and the interviews include questions about each child's participation in federal health care programs and their lead screening history. From the most recent survey sample, CDC estimated in 1997 that 890,000 children aged 1

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through 5 had elevated blood lead levels. CDC has set the level of concern for lead toxicity at 10 or more micrograms of lead per deciliter ( $\mu\text{g}/\text{dl}$ ) of blood. Average blood lead levels for children aged 1 through 5 declined from 15  $\mu\text{g}/\text{dl}$  during 1976 through 1980 to 2.7  $\mu\text{g}/\text{dl}$  during 1991 through 1994. Citing this trend, CDC in 1997 changed its lead screening guidelines to recommend that health officials develop statewide plans that target children who are at specific risk.

However, HHS policies to screen children participating in federal health care programs still remain in place. The federal government has several health care programs serving low-income children that may provide blood lead screenings. Those included in GAO's review are as follows:

- Medicaid, a joint federal and state program, is administered at the federal level by the Health Care Financing Administration. This health care financing program for low-income families covers about one-third of the nation's children aged 1 through 5.
- The Health Center Program, administered by the Health Resources and Services Administration, awards grants to more than 3,000 sites across the nation to provide primary health care services in medically underserved areas. Children served by participating health centers include those covered by Medicaid and an estimated 14 percent of the nation's uninsured children.

GAO also reviewed policies for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), administered by the Department of Agriculture, which serves low-income pregnant women and young children at nutritional risk. Research has shown that children at nutritional risk are especially susceptible to lead poisoning. In addition to delivering nutrition services in more than 2,000 local agencies nationwide, this program helps women and children receive preventive health services such as lead screening.

## Results in Brief

GAO's analysis of CDC's most recent blood lead level and screening survey data shows that the children served by federal health care programs remain at significant risk for elevated blood lead levels. Three-fourths of all the children aged 1 through 5 found to have an elevated blood lead level in CDC's 1991-94 survey were enrolled in Medicaid or WIC or were within the target population for the Health Center Program. This equates to nearly 700,000 children nationwide. More than 8 percent of the surveyed children aged 1 through 5 who were served by federal health care programs had a



harmful blood lead level, a rate almost five times the rate for children who were not in these federal programs.

Despite federal policies, most children in or targeted by federal health care programs have not been screened. For nearly two-thirds of the surveyed children aged 1 through 5 identified by CDC as having elevated lead levels, the blood lead test conducted as part of the CDC survey was the first such test they had received. Projecting these results nationally, more than 400,000 U.S. children in or targeted by federal health care programs have undetected elevated blood lead levels. Other data that GAO analyzed for specific federal health programs tended to corroborate the overall low screening rates reported in CDC's survey and also showed that screening rates vary greatly from state to state and locality to locality.

Screening is often not occurring because federal screening policies are largely not monitored at the federal and state levels. Within Medicaid, for example, only about half of all 51 state programs (including the District of Columbia) that GAO surveyed had screening policies in line with federal policy in the frequency of required screenings, and many states did not monitor providers' lead screening activities. One underlying reason for low screening rates is the widespread belief among providers that lead exposure is no longer a problem in their communities. Most state officials GAO contacted lacked reliable, representative data on the prevalence of elevated blood lead levels and the extent of screening in their states. Another problem is that many children are not receiving adequate preventive health care services, visiting the doctor only when they are sick.

Follow-up treatment for children identified with elevated blood lead levels is complex and potentially resource intensive. Recommended services include follow-up testing, care coordination, and investigations to determine the source of lead exposure, but there are few national data to reliably show the extent to which services are provided to lead-poisoned children. At health centers and state and local health departments visited across the country, GAO found wide variation in the extent of timely follow-up. Specific problems hindering the delivery of care included providers' missing opportunities to perform follow-up tests and children's not returning for follow-up care. Another problem is that most state Medicaid programs do not reimburse for key treatment services.



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## Principal Findings

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### Elevated Blood Lead Levels Remain a Significant Problem for Children Served by Federal Health Care Programs

GAO's analysis of CDC's nationally representative survey data shows that a disproportionate number of the children who have elevated blood lead levels are served by federal health care programs. Although about 40 percent of surveyed children aged 1 through 5 were receiving benefits from Medicaid or WIC or were within the target population of the Health Center Program, more than 77 percent of the children who had elevated blood lead levels in the survey were in or targeted by these programs. This represents 688,000 of the 890,000 children aged 1 through 5 nationwide who were projected to have elevated levels of lead in their blood.

Among surveyed children aged 1 through 5 enrolled in or targeted by federal health care programs, the rate (or prevalence) of elevated blood lead levels was 8.4 percent. This rate was nearly five times the rate for children not in these programs. Analyzing data by individual federal health care programs, GAO found that among children aged 1 through 5 enrolled in Medicaid, the prevalence was greater than 8 percent. For children aged 1 through 5 in low-income and uninsured families (and thus within the target population of the Health Center Program), the prevalence was 6 percent. For children aged 1 through 5 receiving WIC benefits, the prevalence was almost 12 percent.

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### Most Children Served by Federal Health Care Programs Are Not Being Screened for Lead

The CDC survey and Medicaid data also show that children served by federal health care programs are largely not receiving the lead screenings required by federal policies. Reports from parents, guardians and other respondents in CDC's 1991-94 survey show that less than 20 percent of children served by federal health care programs had been screened for lead before participating in the survey. A separate analysis of Medicaid billing data for 1994 and 1995 showed a similar overall screening rate in Medicaid fee-for-service programs for the 15 states where data were available.

GAO also found that screening has not been sufficient to identify most of the children who were in federal health care programs and had elevated blood lead levels. CDC survey data show that most of those projected to have elevated blood lead levels have not been so identified. In other words, the approximate size of the group is known, but the specific children are not. The statistical projections from the survey indicate that



of the estimated 688,000 children aged 1 through 5 who have elevated blood lead levels and are in or targeted by federal health care programs, more than 400,000 have never been screened.

Medicaid data and GAO reviews of health center medical records demonstrate that screening varies from location to location. Billing data from 15 state Medicaid fee-for-service programs show that state-level screening for 1- and 2-year-old children enrolled in Medicaid for a year or longer ranged from less than 1 percent to a high of 46 percent. GAO samples of medical records at seven federally supported health centers across the country, selected because they served high numbers of children in Medicaid and had high numbers of old houses in their area, showed that most of the selected health centers were screening at higher rates than those found in the CDC survey and the 15-state Medicaid information. However, rates still varied—ranging from no children screened at one health center to all children screened at two centers.

## Screening Rates Are Affected by Lack of Oversight and Other Problems

Several problems contribute to the low screening rates found in national and state data. First, federal lead screening policies are often not followed or monitored, as exemplified by the partial implementation of policies by many state and local programs. States have often adopted less rigorous policies, and even these policies are often not monitored. A GAO nationwide survey of Medicaid programs found that almost half of the states had adopted policies less rigorous than the federal policy for screening children in Medicaid (in the frequency of required screenings), and more than one-third were not monitoring providers' lead screening activities. Similarly, three of seven health centers that GAO visited were not complying with all federal lead screening policies. In the states that GAO reviewed, reported screening was highest where states had their own screening laws together with mechanisms to ensure screening (such as requiring proof of screening as a condition of entering daycare or school).

GAO's review and other research point to two other—and more underlying—problems that hinder screening. The first is that many physicians perceive that lead poisoning is not prevalent or serious. A second problem is that many children are still not receiving preventive health care services and hence miss the opportunity for blood lead screenings. For example, health officials said a significant problem was that some families do not seek preventive care services, visiting providers only when children are sick.



Better state and local data on the prevalence of, and screening for, elevated blood lead levels and improved federal, state, and local coordination between lead screening and other preventive care activities are potential areas of action to improve screening. Most state Medicaid agencies and many state lead poisoning prevention programs GAO contacted lacked reliable data showing the prevalence of elevated blood lead levels or the extent of screening of children within the Medicaid program or the state. HHS initiatives to improve the extent to which children receive other preventive health care services, such as immunizations, could provide avenues and models for improving screening if initiatives were coordinated. While the increasing number of Medicaid managed care arrangements provides another opportunity to improve screening, recent research indicates that more than half of state Medicaid managed care contracts have not addressed lead screening responsibilities.

## Several Problems Hinder Efforts to Provide Timely Treatment and Follow-Up Services

For many children who have elevated blood lead levels, several problems hinder the efforts of federally supported health care programs to ensure timely treatment and follow-up services. No national database exists for reliably determining the extent to which recommended follow-up services—such as follow-up testing to ensure that levels decline, care coordination, and environmental investigations to determine the source of lead—are actually provided. The information GAO was able to develop from health centers and health departments in seven states, while limited, indicates gaps in providing needed follow-up, including timely retesting to determine if the problem is continuing.

GAO's medical record review and interviews with health center and health department officials found barriers to providing follow-up testing and other services to children who have elevated blood lead levels, including the problem of providers missing opportunities to perform timely follow-up tests and difficulties in tracking a transient population of children. Another key problem hindering the provision of follow-up services was policy issues related to the resource-intensiveness of recommended treatments for children who have elevated blood lead levels. Federal Medicaid law states that Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program services must cover treatment or other forms of medical assistance necessary to correct or ameliorate conditions identified through screens, but because lead poisoning is an environmentally caused condition, determining appropriate "medical treatments" for elevated blood lead levels can be



difficult. GAO's review found that many states are not covering follow-up services considered important to treat a child who has an elevated lead level. For example, while HHS has for years indicated that lead investigation services are integral to treating a lead-poisoned child, GAO's survey shows that less than half the state Medicaid programs have policies to pay for such services. Most programs also do not have formal agreements with other agencies coordinating the provision of follow-up services. Such formal coordination may be increasingly important as more children are covered by Medicaid managed care, but recent research indicates that Medicaid agencies have largely not considered how managed care providers will need to work with others to provide follow-up services to children who have elevated blood lead levels.

## Recommendations

Specific recommendations to the Secretary of HHS for improving federal support for lead poisoning prevention include (1) developing better state and local information about the extent to which children have elevated blood lead levels, (2) facilitating and monitoring screening for children in federal health care programs, (3) improving managed care contracts, (4) clarifying what services should be available to children identified as having elevated blood lead levels, and (5) enhancing federal efforts to coordinate lead screening and treatment activities with those of other programs serving at-risk children.

## Agency Comments

In its written response to a draft of this report, HHS indicated general agreement with the recommendations and discussed steps that were planned or under way to implement many of them. The response indicated that HHS was committed to ensuring that children served by federal health care programs receive lead screening and necessary treatment services. HHS' response also made a number of suggestions regarding the wording in the draft. These suggestions have been incorporated into the report where appropriate.



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to level blood lead concentrations from 1991 to 1994. Despite dramatic reductions in blood lead levels over the past 20 years, many children, especially those living in older housing or who are poor, are still being harmed by exposure to lead. The Centers for Disease Control and Prevention (CDC) estimates that 800,000 children aged 1 through 5 in the United States have blood lead levels associated with harmful effects on their ability to learn. Lead poisoning has long been considered to be the most serious environmental health threat to children in the United States. Lead is a highly toxic metal that affects virtually every system of the body. At low levels, lead can cause anemia, convulsions, and death. At higher levels, lead can cause irreversible brain damage, learning disabilities, hyperactivity, and attention span deficits. Studies have shown that lead can cause reductions in IQ and even lower levels of intelligence. Because most children who are exposed to lead have no obvious symptoms, a blood test is the best screening method to identify harmful conditions. Lead is most hazardous to the nation's roughly 24 million children under the age of 6, whose still-developing nervous systems are particularly vulnerable to lead and whose normal play activities expose them to lead-contaminated dust and soil. One- and 2-year-old children are at greatest risk because of normal hand-to-mouth activity and the greater mobility during the second year of life that gives them more access to lead in the environment. New and increased knowledge of the health effects of exposure to lead has led to a number of changes that are being implemented or considered safe. In 1991, the U.S. Department of Health and Human Services (HHS) revised the blood lead level threshold from the previous threshold of 25 micrograms per deciliter (µg/dl) to 10 µg/dl. This change was based on new evidence indicating that adverse health effects can occur at levels as low as 10 µg/dl. At this time, HHS is reviewing the U.S. policy for recommending U.S. policy for

## Abbreviations

ATSDR	Agency for Toxic Substances and Disease Registry
CDC	Centers for Disease Control and Prevention
EPA	Environmental Protection Agency
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
HUD	Department of Housing and Urban Development
NHANES	National Health and Nutrition Examination Survey
USDA	Department of Agriculture
WIC	Special Supplemental Nutrition Program for Women, Infants, and Children



# Introduction

Despite dramatic reductions in blood lead levels over the past 20 years, lead poisoning continues to be a significant health risk for young children. Many children, especially those living in older housing or who are poor, are still being harmed by exposure to lead. The Centers for Disease Control and Prevention (CDC) estimates that 890,000 children aged 1 through 5 in the United States have blood lead levels associated with harmful effects on their ability to learn. Lead poisoning has long been considered to be the most serious environmental health threat to children in the United States.

## The Problem of Lead Exposure in Children

Lead is highly toxic and affects virtually every system of the body. At extremely high levels, lead can cause coma, convulsions, and death. At lower levels, studies have shown that lead can cause reductions in IQ and attention span, reading and learning disabilities, hyperactivity, and behavioral problems. Relatively low lead levels are typically not accompanied by overt, identifiable symptoms. Because most children who have elevated blood lead levels have no obvious symptoms, a blood test is the best screening method to identify harmful conditions.

Lead is most hazardous to the nation's roughly 24 million children under the age of 6, whose still-developing nervous systems are particularly vulnerable to lead and whose normal play activities expose them to lead-contaminated dust and soil. One- and 2-year-old children are at greatest risk because of normal hand-to-mouth activity and the greater mobility during the second year of life that gives them more access to lead hazards.

New and increased knowledge of the health effects of exposure to lead has led to concern about lead at levels once considered safe. In October 1991, the Department of Health and Human Services (HHS) revised its level of concern for lead poisoning from the previous threshold of 25 micrograms of lead per deciliter of blood ( $\mu\text{g}/\text{dl}$ ) to 10  $\mu\text{g}/\text{dl}$ . This change was based on scientific evidence indicating that adverse health effects such as impaired learning can occur at levels as low as 10  $\mu\text{g}/\text{dl}$ .<sup>1</sup> At this level, CDC, the HHS agency responsible for recommending U.S. policy for

<sup>1</sup>The National Research Council's Committee on Measuring Lead in Critical Populations generally concurred with CDC in the selection of 10  $\mu\text{g}/\text{dl}$  as the concentration of concern in children. According to the committee, evidence is growing that even very small exposure to lead can produce subtle effects in humans. Therefore, as lead toxicity becomes better understood, future guidelines may establish an even lower level of concern. See National Research Council, Measuring Lead Exposure in Infants, Children, and Other Sensitive Populations (National Academy Press, 1993).



screening young children for lead poisoning, considers blood lead levels to be “elevated” and recommends various actions.

## Prevalence Has Declined Markedly, but Many Children Are Still Affected

While the prevalence of children who have elevated lead levels and the average blood lead levels for the population as a whole have declined dramatically over the past two decades, the number of children who have elevated blood lead levels is still significant. Between the late 1970s and early 1990s, the prevalence of U.S. children aged 1 through 5 years who had elevated blood lead levels dropped from 88 percent to 4.4 percent. HHS and others consider the decline in blood lead levels, associated with the regulatory and voluntary bans on the use of lead in gasoline, household paint, food and drink cans, and plumbing systems, to be a major achievement. Despite this achievement, however, CDC estimated in 1997 that about 890,000 children aged 1 through 5 had elevated blood lead levels.<sup>2</sup> Research also indicates that the risk for lead exposure remains disproportionately high for some groups, including children who are poor, non-Hispanic black, or Mexican American or are living in large metropolitan areas or in older housing. Identifying these children and ensuring that they receive the services they need is a significant public health challenge.

## Sources of Lead Exposure

Children in the United States are exposed to lead primarily by the normal activity of putting their hands, toys, or other objects in their mouths and, to a lesser extent, through inhalation. Because lead is ubiquitous in industrial societies, there are many sources and pathways of lead exposure.

Since lead has been removed from gasoline and food cans, CDC believes that its foremost source in the environment of young children is lead-based house paint. Other major sources are lead-contaminated dust and soil. House dust is often contaminated by lead-based paint that is peeling or deteriorating or disturbed during home renovation or the preparation of painted surfaces for repainting without proper safeguards. Soil contamination can be traced back to deteriorating exterior paint or past widespread use of leaded gasoline.

Lead was a major ingredient in most interior and exterior oil house paint before 1950 and was still used in some paints until 1978, when the residential use of lead paint was banned. The Department of Housing and

<sup>2</sup>Chapter 2 discusses how CDC made this estimate.



Urban Development (HUD) estimates that three-quarters of pre-1980 housing units contain some lead-based paint, and the likelihood, extent, and concentration of lead-based paint increase with the age of the building. In 1995, a federal task force on lead-based paint in the United States estimated that, in all likelihood, somewhere between 5 million and 15 million housing units (of around 90 million occupied units nationwide) contained lead-based paint hazards, of which only a portion were occupied by families with children under age 6 at any given time.<sup>3</sup> However, because families with young children—particularly those in rental housing—tend to move frequently, far more units are occupied by children under age 6 than is shown by the point-in-time estimates of these units.

Other, usually less common, sources of lead in a child's environment include lead-contaminated drinking water (where lead solder and sometimes lead pipes were used in the municipal water system, in the child's home, or both), imported ceramic tableware with lead glaze, old and imported toys or furniture painted with lead-based paint, the clothing of parents whose work or hobby involves high levels of lead, and even home remedies used by some ethnic groups.

## Federal Goals for Reducing Childhood Lead Poisoning

Recognizing that tackling the problem of lead poisoning in children will be a long-term effort, HHS published a strategic plan in 1991 calling for the elimination of childhood lead poisoning in 20 years—by the year 2011.<sup>4</sup> The strategic plan stated that increased childhood lead poisoning prevention activities and national surveillance for elevated lead levels are essential parts of a national strategy to eliminate childhood lead poisoning. HHS reiterated its commitment to eliminating childhood lead poisoning by 2011 by including it as one of the objectives for CDC in its fiscal year 1999 performance plan to the Congress<sup>5</sup>.

Among its department-wide Healthy People 2000 objectives, HHS also established goals to (1) have no children under age 6 with blood lead levels exceeding 25 µg/dl, and (2) have no more than 300,000 children

<sup>3</sup>The Lead-Based Paint Hazard Reduction and Financing Task Force was created under title X of the Housing and Community Development Act of 1992. The task force was created to make recommendations on lead-based paint hazard reduction and financing. See *Putting the Pieces Together: Controlling Lead Hazards in the Nation's Housing*, Report of the Lead-Based Paint Hazard Reduction and Financing Task Force, HUD-1547-LBP (Washington, D.C.: July 1995).

<sup>4</sup>Strategic Plan for the Elimination of Childhood Lead Poisoning (Washington, D.C.: HHS, 1991).

<sup>5</sup>HHS, CDC, Fiscal Year 1999 Justification of Estimates for Appropriations Committees (Washington, D.C.: n.d.).



under age 6 with blood lead levels exceeding 15 µg/dl by 2000.<sup>6</sup> For its Healthy People 2010 objectives, HHS has drafted a more ambitious goal than that established for 2000: No children aged 1 through 5 should have blood lead levels exceeding 10 µg/dl.<sup>7</sup>

## Many Federal Agencies Are Involved in Identifying and Treating Childhood Lead Poisoning

Reflecting the complexity of childhood lead exposure and treatment, numerous federal agencies have responsibilities for screening and treatment. Within HHS, these activities are centered on the guidelines and grant programs of CDC, the Medicaid program administered by the Health Care Financing Administration (HCFA), and the health centers funded by the Health Resources and Services Administration (HRSA).

- CDC is the federal agency responsible for issuing recommendations for screening and treating young children for lead poisoning. CDC gathers information on the extent of lead poisoning under the National Health and Nutrition Examination Survey (NHANES), a survey that gathers nationally representative data on the health and nutrition of the U.S. population through direct physical examinations and interviews. CDC also administers the Childhood Lead Poisoning Prevention and Surveillance Grant Program, awarding about \$27 million in grants to more than 53 state and local public health departments in fiscal year 1998. The CDC grant program was authorized by the Lead Contamination Control Act of 1988 and was amended by the Preventive Health Amendments of 1992. CDC is required to report annually to the Congress on the number of children screened, the age and racial or ethnic status of the children screened, the severity of the extent of children's blood lead levels, and the sources of payment for the screenings.
- Medicaid is a major health care financing program for low-income families. As a joint federal and state program, Medicaid funds medical care for about one-third of all children aged 1 through 5 in the United States. HCFA's Medicaid policy for addressing childhood lead poisoning prevention was established by the Omnibus Budget Reconciliation Act of 1989, which required that Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services include blood lead laboratory tests appropriate for age and risk factors.<sup>8</sup> EPSDT services also include treatment or other forms of medical assistance for children who have elevated blood lead levels. While some Medicaid services are provided under a traditional

<sup>6</sup>National Center for Health Statistics, Healthy People 2000 Review 1995-96 (Hyattsville, Md.: Public Health Service, 1996).

<sup>7</sup>The Healthy People 2010 initiative was in draft form at the time of our review.

<sup>8</sup>EPSDT is a comprehensive prevention and treatment program for Medicaid recipients under 21 years of age.



fee-for-service arrangement, at least 40 states also contracted with managed care organizations to provide health care services to some children covered by Medicaid in 1997.<sup>9</sup>

- HRSA's Health Center Program supports more than 3,000 health center sites that provide primary care services, including lead screening and treatment, in medically underserved areas.<sup>10</sup> Federal funding for the Health Center Program exceeded \$820 million in fiscal year 1998. The Public Health Service Act defines required primary health services for health centers as including screenings for elevated blood lead levels. The act requires health centers to provide these services to all residents of the area served by a center, and the centers' target population includes families whose incomes are less than 200 percent of the federal poverty level. Approximately 85 percent of health center patients are at this income level or below. In 1997, 1.2 million children under age 5 received care at health centers. Four of every 10 patients seen at these health centers in 1997 were uninsured, and more than 3 of every 10 were covered by Medicaid. HRSA provided estimates that health centers served around 14 percent of the nation's uninsured children in 1995.

Other federal programs help address childhood lead poisoning, but the extent of their contribution is generally unknown. HHS' Maternal and Child Health Block Grant may fund lead poisoning prevention activities in some states that have identified lead poisoning as a critical health concern. Head Start, another program that HHS administers, also may fund lead screenings. Head Start's primary goal is to improve the social competence of children in low-income families. To support this goal, Head Start delivers a wide range of services to disadvantaged young children, serving about 782,000 children in program year 1996-97. These services include medical and nutrition services such as lead screening.

The Department of Agriculture's (USDA) Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) has also been involved in lead screening for children. WIC was established to counteract the negative effects of poverty on prenatal and pediatric health and combines direct nutritional supplementation, nutrition education and counseling, and

<sup>9</sup>The State Children's Health Insurance Program, established under the Balanced Budget Act of 1997 to address the problem of uninsured children, will provide another means of federal support for childhood lead poisoning prevention. States can expand their current Medicaid program, establish a new program, or implement a combination of the two approaches.

<sup>10</sup>The Health Center Program, authorized under section 330 of the Public Health Service Act, was formerly four separate programs: community health centers, migrant health centers, homeless health centers, and centers for residents of public housing. Before the Health Center Consolidation Act of 1996 (P.L. 104-299, Oct. 11, 1996) these programs were authorized under sections 329, 330, 340, and 340A of the Public Health Service Act.



increased access to health care and social service providers for pregnant, breastfeeding, and postpartum women and their infants and children up to 5 years of age. While the cornerstone of WIC's mission is to provide nutrition services, WIC agencies are also charged with assisting WIC participants to obtain and use preventive health care services. By providing on-site health services or referring to other agencies, WIC links participants to appropriate health-care providers. Such services may include lead screening.

HUD also administers a grant program to identify and control lead-based paint hazards in low-income privately owned housing. From 1992 to 1995, HUD awarded \$280 million to state and local governments for this purpose. In fiscal year 1996, it awarded an additional \$55 million to 20 grantees. The Environmental Protection Agency (EPA) regulates work practice standards for lead hazard evaluation and control, develops training courses, sets minimum requirements for contractor training and qualification, makes grants to states and approves state programs for certifying lead contractors and accrediting trainers, and defines hazardous levels of lead in dust, paint, and bare soil. EPA's grant program had awarded \$36 million to 46 states, the District of Columbia, and 27 Native American tribal nations as of February 1997.

## Objectives, Scope, and Methodology

The ranking minority member of the House Committee on Government Reform and Oversight asked us to address

1. the risk of lead poisoning faced by young children served by federal health care programs,
2. the extent to which children in these programs have been screened for this condition,
3. key reasons why screenings may not be occurring, and
4. problems that federal health care programs face in ensuring that children who have been determined to have harmful lead levels in their blood receive timely follow-up treatment and other services.

To address these objectives, we reviewed relevant legislation, studies, and policy documents and interviewed officials from (1) CDC, HCFA, HRSA's Bureaus of Primary Health Care and Maternal and Child Health, and HHS' Administration of Children and Families; (2) USDA, HUD, EPA, the Agency for



Toxic Substances and Disease Registry, and the Association of State and Territorial Health Officials; (3) health centers receiving federal grant funds; (4) state and local lead poisoning prevention programs; (5) the National Lead Information Center, the Alliance to End Childhood Lead Poisoning, and other experts in lead poisoning prevention; (6) the American Academy of Pediatrics and other health care providers; and (7) programs the director of the National Lead Information Center cited as models for treating children for lead exposure—Montefiore Medical Center in the Bronx, New York, the Children's Hospital in Boston, Massachusetts, and the Kennedy Krieger Institute in Baltimore, Maryland.

To assess the degree of harmful lead levels among young children in federal health care programs as well as the extent to which these children have been screened for lead poisoning, we analyzed data from CDC's most recently released NHANES.<sup>11</sup> This survey contains nationally representative information on the health and nutrition of the U.S. population gathered through direct physical examinations and interviews. Our February 1998 report and May 1998 letter to the ranking minority member of the House Committee on Government Reform and Oversight contained the initial results of our analysis of the NHANES related to the Medicaid population.<sup>12</sup> The results pertaining to the objectives in this comprehensive review are incorporated in this report. Appendix I explains in further detail our methodology for analyzing the NHANES data.

To determine the percentage of children covered by Medicaid who received a blood lead test in selected states, we analyzed data in HCFA's State Medicaid Research File for 15 states. Appendix II explains in further detail our methodology for analyzing the Medicaid billing data. To assess state Medicaid policies and procedures, we sent a questionnaire to the director of the Medicaid program in all 50 states and the District of Columbia. We received a 100-percent response rate from Medicaid directors reporting on (1) program coverage of services for children who have elevated blood lead levels, (2) the availability of data on the prevalence of elevated blood lead levels in the Medicaid population, (3) Medicaid or other state monitoring of lead screening services, and (4) Medicaid or other state monitoring of treatment for elevated lead levels. The respondents also provided copies of their state Medicaid

<sup>11</sup>The NHANES has been conducted periodically since 1960. This analysis is from Phase 2 (1991-94) of NHANES III, HHS/CDC, National Center for Health Statistics, National Health and Nutrition Examination III, 1988-94, NCHS CD-ROM, Series 11, No. 1A, ASCII Version, July 1997.

<sup>12</sup>Medicaid: Elevated Blood Lead Levels in Children (GAO/HEHS-98-78, Feb. 1998) and Children's Health: Elevated Blood Lead Levels in Medicaid and Hispanic Children (GAO/HEHS-98-169R, May 1998).



policies and any formal agreements they had with health departments, housing departments, or others for ensuring that lead screening and treatment services were provided to children enrolled in Medicaid. Appendix III explains in further detail our survey methodology.

Although we interviewed HHS officials who administer the Maternal and Child Health Block Grant program and the Head Start program, our work with these programs was limited. While they can support childhood lead poisoning prevention activities, national data on how much lead screening is conducted through the block grants or Head Start are not available. Many of the children served by these programs are also served by the programs we did review—that is, they are served by the CDC grant programs, are covered by Medicaid, or live in areas served by health centers receiving federal grants. Because our focus was on federal activities to screen and treat children for elevated blood lead levels, we did not assess the HUD and EPA lead programs. We previously reported on issues concerning HUD and EPA programs related to lead poisoning prevention.<sup>13</sup> Appendix IV contains further details on federal screening and treatment policies.

We also visited seven federally supported health centers in Atlanta, Georgia; Everett, Washington; New Bedford, Massachusetts; Brooklyn, New York; Philadelphia, Pennsylvania; San Antonio, Texas; and Watsonville, California, for the purpose of reviewing two samples of medical records at each health center. We assessed (1) the screening of 1- and 2-year-old children visiting the center in 1996 and (2) the follow-up of children identified with elevated blood lead levels in 1996. We selected the health centers for a mix of geographic areas and to target areas where children had a higher risk for lead exposure, based on the number of children covered by Medicaid seen at the health centers in 1996 and the number of houses built before 1950 in the centers' zip codes. See appendixes V and VI for more details about our methodology for the medical record review at the health centers.

We met with officials from six state and city childhood lead poisoning prevention and surveillance programs that received CDC grant funding.

<sup>13</sup>See *Lead-Based Paint Hazards: Abatement Standards Are Needed to Ensure Availability of Insurance* (GAO/RCED-94-231, July 15, 1994), *Lead-Based Paint Poisoning: Children in Section 8 Tenant-Based Housing Not Adequately Protected From Lead Poisoning* (GAO/RCED 94-137, May 13, 1994), *Toxic Substances: Status of EPA's Efforts to Develop Lead Hazard Standards* (GAO/RCED-94-114, May 16, 1994), *Lead-Based Paint Poisoning: Children Not Fully Protected When Federal Agencies Sell Homes to Public* (GAO/RCED-93-38, Apr. 15, 1993), *Lead-Based Paint Poisoning: Children in Public Housing Are Not Adequately Protected* (GAO/RCED-93-138, Sept. 17, 1993), and *Toxic Substances: Federal Programs Do Not Fully Address Some Lead Exposure Issues* (GAO/RCED-92-186, May 15, 1992).



These programs, generally located near the health centers we visited, included programs run by the states of California, Massachusetts, Texas, and Washington as well as New York City and Philadelphia. At each program, we discussed their activities and assessed the extent to which they were tracking children who had higher blood lead levels (20 µg/dl or higher) who were in our record reviews at the health centers we visited. Where applicable, we also discussed follow-up treatment activities with local health departments. We also discussed factors that aided or impeded these follow-up activities. Finally, we obtained copies of relevant legislation and regulations in effect at the time of each visit (conducted between late 1997 and early 1998). Appendix VII contains further details about our methodology and summarizes information obtained on state and local requirements.

We carried out our review from June 1997 through December 1998 in accordance with generally accepted government auditing standards.



# Elevated Blood Lead Levels Remain a Significant Problem for Children Served by Federal Health Care Programs

Our analysis of CDC survey data shows that elevated blood lead levels remain a significant problem for children who are served by federal health care programs. The children participating in CDC's nationally representative survey who were enrolled in or targeted by federal health care programs were much more likely than other children to have elevated blood lead levels. Three-fourths of the children in the survey found to have elevated blood lead levels were enrolled in Medicaid or WIC or were targeted by HRSA's Health Center Program.<sup>14</sup>

Data CDC gathered in its NHANES survey provided the basis for its estimate that elevated blood lead levels are found in about 890,000, or 4.4 percent, of U.S. children aged 1 through 5.<sup>15</sup> Most recently conducted during 1991-94, the NHANES gives comprehensive physical examinations and in-depth interviews to a nationally representative sample of the population (including almost 2,400 children aged 1 through 5 in the most recent survey). A blood lead test is included in the physical examination. Demographic, health insurance, income, and other information is also gathered in the interviews and incorporated into the CDC database.

Survey results showed that children who had elevated blood lead levels were likely to be receiving health care benefits or services through federal programs. Children who were enrolled in or targeted by federal health care programs constituted about 40 percent of all 1- through 5-year-olds in the sample but more than 77 percent of the 1- through 5-year-olds who had elevated blood lead levels. Projecting the sample results to the population at large, we estimate that 688,000 of the estimated 890,000 children who have elevated blood lead levels nationwide are enrolled in Medicaid or WIC or are within the target population served by the Health Center Program.<sup>16</sup>

The prevalence of elevated blood lead levels for the surveyed children enrolled in Medicaid or WIC or living in low-income and uninsured families targeted by the Health Center Program was about 8.4 percent—that is, 8.4 percent of these children had elevated blood lead levels. This rate was nearly five times the 1.7-percent prevalence found among the children not enrolled in or targeted by these federal health care programs.

<sup>14</sup>While WIC is generally considered a nutrition program, for our purposes we refer to it as one of the health care programs that we reviewed.

<sup>15</sup>Centers for Disease Control and Prevention, "Updated: Blood Lead Levels—United States, 1991-1994," *Morbidity and Mortality Weekly Report*, Vol. 46, No. 7 (1997), pp. 141-46, and *Morbidity and Mortality Weekly Report*, Vol. 46, No. 26 (1997), p. 607.

<sup>16</sup>The remaining children who had elevated blood lead levels were living in families whose incomes were more than 130 percent of the poverty level, had some form of health insurance besides Medicaid, and were not receiving WIC benefits.



The program-by-program results together with projections of how many children in each program have elevated blood lead levels are presented below. Because some children are eligible for more than one program, the estimates total more than 688,000.

## Results for Surveyed Children Enrolled in Medicaid

Our analysis of the NHANES data shows that about 1 in every 12, or 8.5 percent, of the 1-through 5-year-olds who were enrolled in Medicaid had an elevated blood lead level. Of particular note, NHANES data indicated that Medicaid children constitute the majority of children who have elevated blood lead levels high enough to warrant clinical management, including evaluations for complications of lead poisoning, environmental investigations, and other services. The NHANES data show that at least 83 percent of children aged 1 through 5 who had higher levels of lead toxicity (20 µg/dl or more) were enrolled in Medicaid. Projecting the NHANES results for the surveyed children in Medicaid to the national level, we estimate that 535,000 of the 890,000 children who have elevated blood levels are in families that have Medicaid health care coverage.<sup>17</sup>

## Results for Surveyed Children in WIC

Children at nutritional risk—those targeted by the WIC program—are especially susceptible to lead poisoning.<sup>18</sup> For example, iron deficiency has been shown to increase the toxicity of lead. Our analysis of NHANES data for children in families receiving WIC benefits found that 1 in 9, or 12 percent, of these children had an elevated blood lead level. This rate translates to an estimate that 452,000 of the 890,000 children who have elevated blood lead levels are members of families receiving WIC benefits, including 319,000 children who are also covered by Medicaid.

<sup>17</sup>We previously reported this portion of our analysis in GAO/HEHS-98-78. In another analysis in which we looked at prevalence and screening for Medicaid children aged 1 and 2, we found that nearly 10 percent of children in Medicaid aged 1 through 2 had elevated levels of lead in their blood. See GAO/HEHS-98-169R.

<sup>18</sup>See National Research Council, Measuring Lead Exposure in Infants, Children, and other Sensitive Populations (Washington, D.C.: 1993).



**Chapter 2**  
**Elevated Blood Lead Levels Remain a**  
**Significant Problem for Children Served by**  
**Federal Health Care Programs**

## Results for Surveyed Children Within the Health Center Target Population

Although children receiving Medicaid benefits may receive their care at federally supported health centers, these centers target those with the greatest risk of going without medical care—often children in families whose income is low and who also lack health insurance.<sup>19</sup> Within this group, our analysis of NHANES data shows that about 1 of every 16 children, or 6 percent, had an elevated blood lead level. Projecting this rate to the entire population, an estimated 67,000 of the 890,000 children who have elevated blood levels are in low-income and uninsured families and thus within the target population for the Health Center Program.

<sup>19</sup>We defined “low-income family” as one whose income was less than or equal to 130 percent of the federally defined poverty level at the time of the NHANES survey. We used this level because CDC in earlier NHANES analyses defined incomes lower than this level as low-income. (See Morbidity and Mortality Weekly Report, Vol. 46, No. 7 (1997), p. 141.)



# Most Children Served by Federal Health Care Programs Are Not Being Screened for Elevated Blood Lead Levels

Despite federal policies to ensure that children in federal health care programs are screened for elevated blood lead levels, most children are not being screened. Our analysis of NHANES data shows that only 18 percent of all surveyed children enrolled in or targeted by federal health care programs had been screened before participating in the survey. This means that most of the children who are likely to have elevated blood lead levels—more than 400,000—have not been identified as having this condition. Our analysis of 15 states' Medicaid billing data similarly indicates that overall screening is low, and information from the health centers we visited shows that screening varies greatly from state to state and location to location.

## Federal Policies Are Designed to Ensure That Children Are Screened

CDC, HCFA, HRSA, and USDA have issued guidelines and requirements regarding the extent to which children in federal health care programs should be screened for elevated blood lead levels. CDC's general guidelines have recently changed: Guidelines issued in October 1991 called for virtually all children aged 1 through 5 to be screened, but CDC's November 1997 guidelines recommended that state health officials develop statewide plans for childhood lead screening and better target children who are at specific risk. Citing the declining trend in average blood lead levels and generally low screening rates, CDC revised its guidelines to both relax universal screening recommendations in low-risk areas and increase the identification of children in high-risk communities and populations. However, CDC maintains that, in general, children who receive Medicaid or other federal health benefits should be screened unless reliable, representative blood lead level data demonstrate the absence of lead exposure.<sup>20</sup>

HCFA and HRSA have required that Medicaid providers and health centers receiving federal grants provide lead screening services. Federal Medicaid policy for lead screening was established by the Omnibus Budget Reconciliation Act of 1989, which required that Medicaid EPSDT services include blood lead level laboratory tests appropriate for age and risk factors. HCFA's Medicaid manual has specifically required since 1992 that, in line with CDC's recommendations, children enrolled in Medicaid be screened for elevated blood lead levels at a minimum at ages 12 and 24 months, and through 72 months if previously unscreened. HRSA policy was established in 1992 when Public Law 102-531 amended the Public Health Service Act to include lead screening among the primary services that

<sup>20</sup>CDC, Screening Young Children for Lead Poisoning: Guidance for State and Local Public Health Officials (Atlanta: Nov. 1997).



health centers provide. HRSA policy calls for health centers to establish lead screening protocols that are consistent with CDC's guidelines, including risk assessments at well child visits and an initial blood lead test at at least 12 months.<sup>21</sup> Details of these federal lead screening policies appear in appendix IV.

USDA does not require that WIC programs screen participating children. Instead, WIC programs are encouraged to ask during nutrition screening whether children have had a blood lead test and, if not, to refer them to a lead screening provider.<sup>22</sup> Such preventive health services might be financed by other federal programs such as Medicaid, because many WIC recipients are also eligible for Medicaid. However, research has shown that WIC is the single largest point of access to health-related services for low-income preschool children.<sup>23</sup>

## National Survey Data Show That Only One in Five Children Has Been Screened

Despite federal policies to ensure that children in federal health care programs receive screening services, our analysis of NHANES and Medicaid data indicates that only about 18 percent have been screened. The NHANES database can be used to estimate lead screening for both the population as a whole and various groups such as those eligible for federal health care program benefits because it contains responses from participating parents, guardians, and others as to whether the children have been screened for lead. Screening rates for children aged 1 through 5 in or targeted by the three federal health care programs ranged from 17 to 19 percent, compared with 7 percent for children not in any of these programs (see table 3.1).

<sup>21</sup>Specifically, HRSA policy indicates that each well-child visit and other pediatric visits as appropriate from age 6 months to 6 years should assess risk of exposure to lead. High-risk children should receive an initial blood lead test at age 6 months or when they are determined to be at high risk. Low-risk children should receive an initial blood lead test at age 12 months.

<sup>22</sup>Elevated blood lead levels may make children eligible for WIC if other qualifying criteria are met. In June 1998, when USDA set national eligibility standards for its WIC program, it included an elevated blood lead level as a qualifying condition for nutritional risk. In earlier years, WIC had a more significant role in lead screening, as discussed later in this report.

<sup>23</sup>According to researchers, approximately 5 to 7 million infants and children younger than 5 years old participated in WIC monthly during 1997. WIC participants generally visit clinics every 2 to 3 months to receive nutrition services and food vouchers, and more comprehensive health status evaluations are conducted every 6 to 12 months during certification visits. See Abigail Shefer and Jim Mize, "Primary Care Providers and WIC: Improving Immunization Coverage Among High-Risk Children," *Pediatric Annals*, Vol. 27, No. 7 (1998), pp. 428-33.



**Chapter 3**  
**Most Children Served by Federal Health**  
**Care Programs Are Not Being Screened for**  
**Elevated Blood Lead Levels**

**Table 3.1: Estimated Lead Screening Rates for Children Aged 1 Through 5**

	Percent screened
All children aged 1-5	11
Children enrolled in Medicaid <sup>a</sup>	19
Low-income and uninsured children <sup>b</sup>	17
Children enrolled in WIC <sup>c</sup>	18
Children not covered by Medicaid or WIC and not low-income and uninsured	7

<sup>a</sup>Our previous analysis of lead screening for Medicaid children aged 1 through 2 showed a screening rate of 21 percent. See *Children's Health: Elevated Blood Lead Levels in Medicaid and Hispanic Children* (GAO/HEHS-98-169R, May 18, 1998).

<sup>b</sup>This population of children is within the target population for the Health Center Program.

<sup>c</sup>Children participating in WIC may also be participating in the Medicaid program or may have low incomes and no health insurance. These figures are for ages 1 through 4, since WIC is for children through age 4 only.

Since the NHANES analysis on lead screening is based on parents' and guardians' reports of whether participating children have been screened, it is subject to the accuracy of their awareness and recall. However, it is supported by other data reflecting screening rates for certain children enrolled in Medicaid. We analyzed data from HCFA's State Medicaid Research File to assess the extent to which individual state Medicaid programs had been billed for lead tests for children receiving Medicaid coverage for a year or more.<sup>24</sup> This analysis of 1994 and 1995 data from 15 state Medicaid fee-for-service programs showed a screening rate similar to that of the NHANES data. On average, state Medicaid programs provided lead tests for 21 percent of 1- and 2-year-old children covered for a full year by Medicaid. While these billing data provide information only for children covered by Medicaid fee-for-service (rather than managed care) arrangements, data reported to us by state Medicaid agencies were the basis for our estimate that as of June 1997, about 60 percent of

<sup>24</sup>HCFA's State Medicaid Resource File contains Medicaid fee-for-service information on eligibility, billing claims, and utilization for states that participate in the Medicaid Statistical Information System. Billing data are limited to the extent that they do not provide information on provided services for which no reimbursement was sought. For this reason, we excluded from our analysis (1) children receiving Medicaid for less than 1 year, (2) children with any indication of having other insurance coverage, and (3) any data for states that indicated to us that their public health laboratory performed blood lead tests at no fee to the Medicaid program. Further details on our use of state Medicaid data appear in appendix II.



Medicaid-enrolled children had fee-for-service arrangements.<sup>25</sup> National data on lead screening within Medicaid managed care programs were not available.

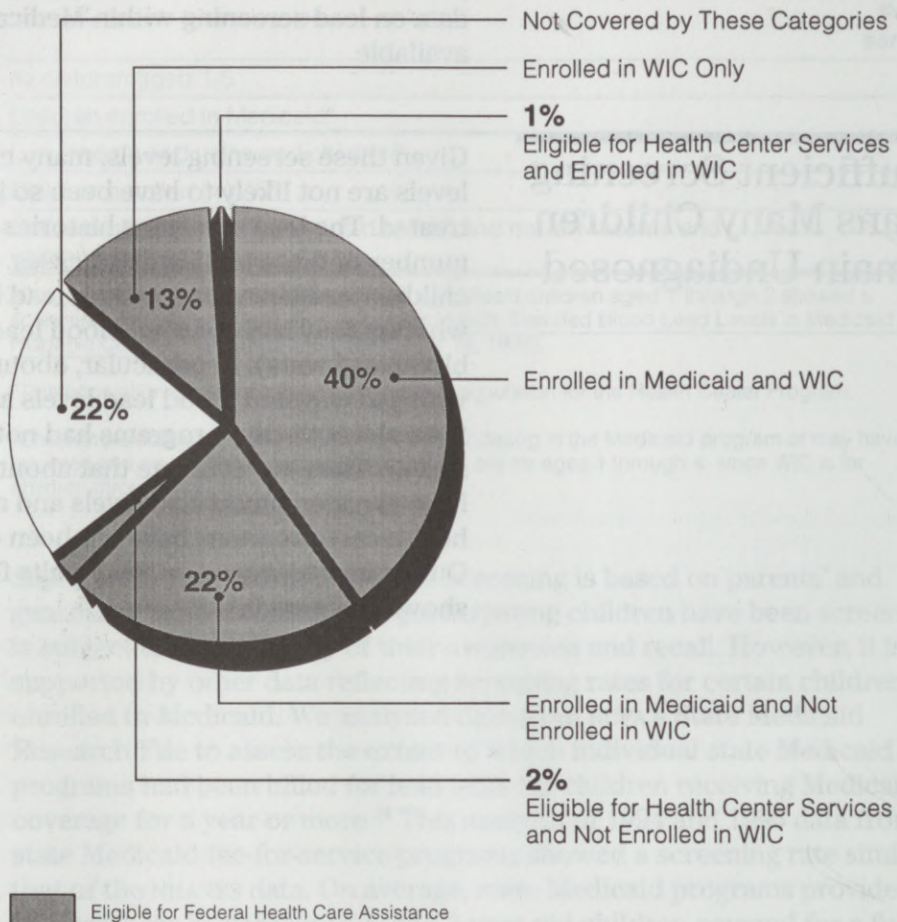
## Insufficient Screening Means Many Children Remain Undiagnosed

Given these screening levels, many children who have elevated blood lead levels are not likely to have been so identified and therefore have not been treated. The lead screening histories in the NHANES allow us to estimate the number of these undiagnosed cases. That is, the survey data show whether children had been screened for lead before participating in the survey and whether they had elevated blood lead levels (as identified through NHANES blood lead tests). In particular, about two-thirds of participating children who had elevated blood lead levels and were enrolled in or targeted by federal health care programs had not received a blood lead test before the survey. Thus, we estimate that about 436,000 of the 688,000 children who have elevated blood lead levels and are enrolled in or targeted by federal health care programs have not been diagnosed as having this condition. Our estimates, based on the results for children aged 1 through 5, are shown in figure 3.1.

<sup>25</sup>HCFA does not maintain complete screening data on children enrolled in Medicaid who are under age 6 and have managed care arrangements. Since the number of people with managed care arrangements has been increasing, the proportion of Medicaid children with fee-for-service arrangements in the earlier years of our analysis (1994 and 1995) is likely to have been higher.



**Figure 3.1: Estimated Number of Children Aged 1 Through 5 Years Who Have Undetected Elevated Blood Lead Levels by Federal Health Care Assistance Category**



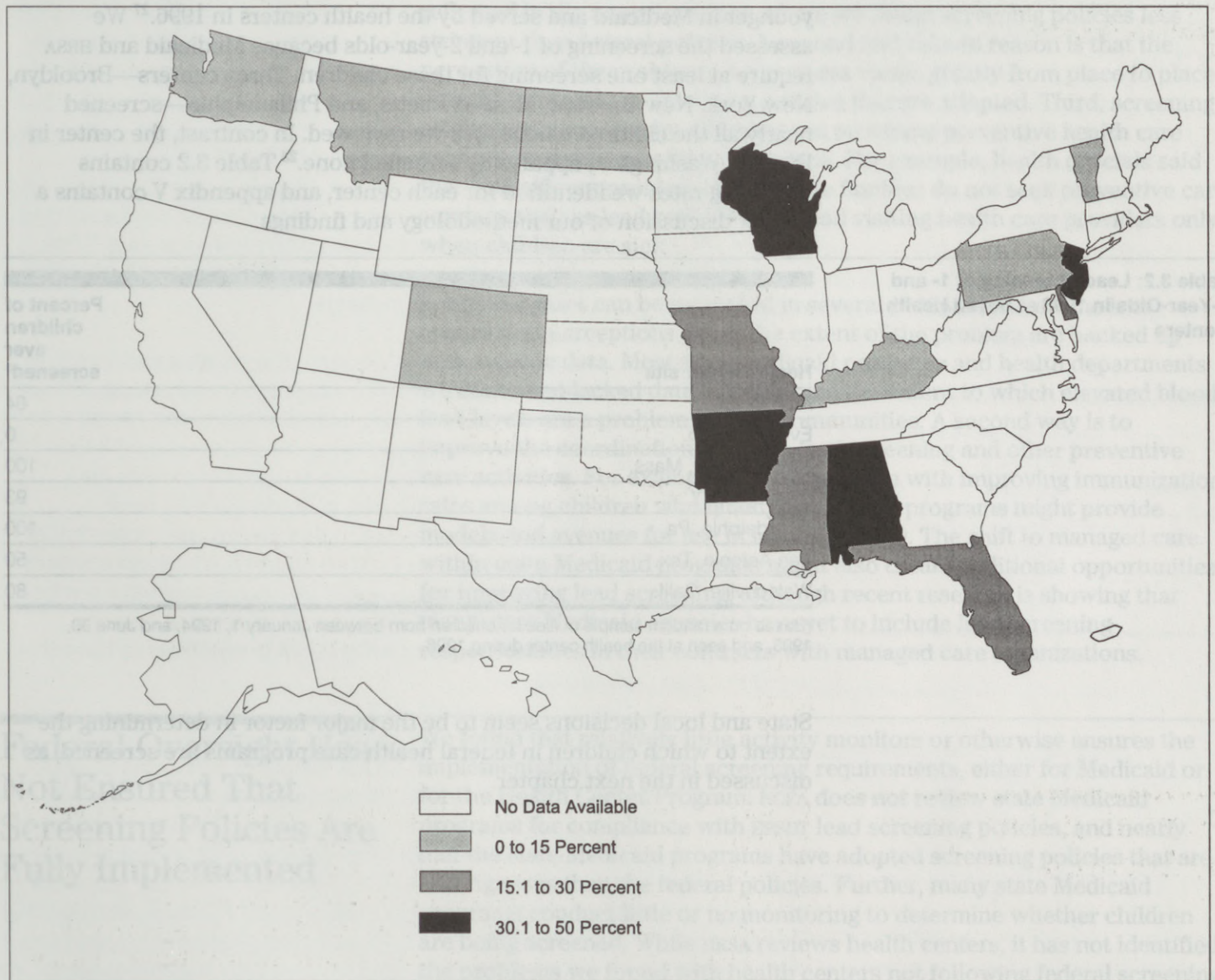
## Screening Rates Vary by Location

Information from the Medicaid billing database we analyzed for 15 states and our review of seven health centers indicate that the extent to which children are screened for elevated blood lead levels varies widely from location to location. State Medicaid agency screening rates in fee-for-service arrangements ranged from less than 1 percent of children aged 1 through 2 in Washington to about 46 percent in Alabama.<sup>26</sup> Figure 3.2 provides the results of this analysis by state.

<sup>26</sup>We contacted Washington and Alabama health departments to determine whether these rates were consistent with data on lead screening they collected. Both confirmed that these screening rates were consistent with those reported in their states. For example, in 1996, less than 1 percent of all children in Washington had been screened for lead poisoning.



Figure 3.2: State Medicaid Billing Rates for Blood Lead Laboratory Tests for Children Aged 1 and 2 in 1994 and 1995



Most of the seven health centers we reviewed were screening at rates much higher than the overall rates we found in the NHANES and Medicaid data. However, as with state Medicaid programs, screening varied widely



between the seven centers. Within 7 of 10 HHS regions, we selected centers that could be considered to be in high-risk areas on the basis of (1) the number of pre-1950 homes and (2) the number of children aged 4 and younger in Medicaid and served by the health centers in 1996.<sup>27</sup> We assessed the screening of 1- and 2-year-olds because Medicaid and HRSA require at least one screening for these children. Three centers—Brooklyn, New York, New Bedford, Massachusetts, and Philadelphia—screened nearly all the children whose files we reviewed. In contrast, the center in Everett, Washington, apparently screened none.<sup>28</sup> Table 3.2 contains screening rates we identified for each center, and appendix V contains a further discussion of our methodology and findings.

**Table 3.2: Lead Screening of 1- and 2-Year-Olds in 1996 at Seven Health Centers**

Health center site	Percent of children ever screened <sup>a</sup>
Atlanta, Ga.	64
Everett, Wash.	0
New Bedford, Mass.	100
Brooklyn, N.Y.	93
Philadelphia, Pa.	100
San Antonio, Tex.	50
Watsonville, Calif.	80

<sup>a</sup>Based on a random sample of files for children born between January 1, 1994, and June 30, 1995, and seen at the health center during 1996.

State and local decisions seem to be the major factor in determining the extent to which children in federal health care programs are screened, as discussed in the next chapter.

<sup>27</sup>We used this age group because HRSA requires health centers to report for it. See app. V for a more detailed discussion of our methodology and findings at health centers.

<sup>28</sup>Officials in Everett told us that they had performed only three lead tests in 1997 and could not identify screenings for 1996, the year we reviewed. Officials at the Washington State Department of Health, where the state's registry of lead tests is maintained, confirmed that this center reported conducting only three tests in 1993-98. As a result, we did not specifically review medical records to determine the center's screening rate.



# Screening Rates Are Affected by Lack of Oversight and Other Problems

Lead screening rates in federal health care programs are low for several reasons. One is that federal and state agencies often do not monitor or otherwise ensure the implementation of federal screening policies. This is reflected in the many locations where we found screening policies less stringent than federal policies. A second and related reason is that the perception of the problem's seriousness varies greatly from place to place, directly affecting the screening policies that are adopted. Third, screening efforts are hampered by difficulties in providing preventive health care services to children in these programs. For example, health officials said that a significant problem is that some families do not seek preventive care services such as lead screening, instead visiting health care providers only when children are sick.

Screening rates can be increased in several potential ways. One is to ensure that perceptions about the extent of the problem are backed up with reliable data. Most state Medicaid programs and health departments we contacted lacked data to determine the extent to which elevated blood lead levels are a problem in their communities. A second way is to improve the coordination between lead screening and other preventive care activities. For example, HHS' experience with improving immunization rates among children who qualify for federal programs might provide models and avenues for use in lead screening. The shift to managed care within state Medicaid programs might also create additional opportunities for improving lead screening, although recent research is showing that many state Medicaid agencies have yet to include lead screening responsibilities in their contracts with managed care organizations.

## Federal Oversight Has Not Ensured That Screening Policies Are Fully Implemented

We found that relatively little activity monitors or otherwise ensures the implementation of federal screening requirements, either for Medicaid or for the Health Center Program. HCFA does not review state Medicaid programs for compliance with EPSDT lead screening policies, and nearly half the state Medicaid programs have adopted screening policies that are less rigorous than the federal policies. Further, many state Medicaid programs conduct little or no monitoring to determine whether children are being screened. While HRSA reviews health centers, it has not identified the problems we found with health centers not following federal screening policies. However, screening rates are highest where the states have their own statutes or regulations with specific screening requirements and other ways of ensuring compliance.



## Lack of HCFA Oversight Means State Medicaid Screening Policies Are Often Less Rigorous Than HCFA's

HCFA does not monitor state Medicaid agencies' implementation of lead screening policies. A HCFA official told us that the agency assumes that the states are providing EPSDT services as specified in HCFA policy and does not specifically review them for comparability with federal policies. HCFA does set and monitor performance standards regarding certain EPSDT services such as preventive vision, dental, and hearing screening. These standards do not include lead screening.

Many state Medicaid programs do not match HCFA's policy that lead screening services be provided to children at 12 and 24 months of age, and through 72 months if previously unscreened.<sup>29</sup> Specifically, we found that 24 of the 51 states have policies that are less rigorous than HCFA's.<sup>30</sup> For example, 2 states require screening only once, at either 12 or 24 months, and 7 do not require minimum screening tests.

Many state policies do not follow HCFA's policy of screening children aged 36 months through 72 months if previously unscreened, which could leave many children with undetected and untreated elevated blood levels. Specifically, 21 states do not require screening for children aged 3 through 5 who have not been previously screened. An analysis of NHANES data shows that about 41 percent of all children in Medicaid who have undetected elevated blood lead levels are in this age group. Projected to the entire population, this represents 146,000 children who have elevated blood lead levels, are in Medicaid, are aged 3 through 5, and have not been screened. To the extent that they reside in the 21 states that have no screening requirement, these 3- through 5-year-olds are likely to have their conditions go undetected.

HCFA has recently amended its policy and in so doing has clarified an ambiguity that may have contributed to the variety of screening policies we found. Until recently, HCFA's Medicaid manual contained potentially conflicting guidance regarding blood screening tests. It stated that blood lead screening was required for all children at least at 12 and 24 months of age, but it also stated that physicians should use their medical judgment in determining the applicability of the laboratory tests. The manual indicated that laboratory tests (including that for lead toxicity) should be conducted "as appropriate." In September 1998, HCFA changed the manual to read,

<sup>29</sup>HCFA's 1993 state Medicaid manual indicated that a child between the ages of 24 months and 72 months who had not been screened for blood lead must be screened immediately. HCFA's 1998 Medicaid manual change indicated that children between the ages of 36 months and 72 months must receive a screening blood lead test if they have not been previously screened for lead poisoning.

<sup>30</sup>The District of Columbia is counted as a state.



“With the exception of lead toxicity screening, physicians providing screening services under the EPSDT program use their medical judgment in determining the applicability of the laboratory tests or analyses to be performed. Lead toxicity screening must be provided.”<sup>31</sup>

State Medicaid Oversight Is Often Lacking

Many state Medicaid agencies are not monitoring Medicaid providers’ lead screening activities. We surveyed all 51 state Medicaid agencies to see whether and how they, the health department, or others monitor fee-for-service and managed care providers to ensure that children in Medicaid were screened.<sup>32</sup> Thirty states indicated that they monitor either fee-for-service providers or managed care providers to some degree. Twenty-two of 47 states with children in fee-for-service care provide some degree of monitoring; 26 of 41 states with children in managed care do so (see table 4.1). Most do so by auditing a sample of medical records.

Table 4.1: State Lead Screening Monitoring of Children in Medicaid

	States that monitor lead screening for children in Medicaid	Type of monitoring <sup>a</sup>		
		Reporting requirements	Audits of medical records	Review of billing data
Fee-for-service providers <sup>b</sup>	22	4	16	6
Managed care providers <sup>c</sup>	26	10	22	7

<sup>a</sup>Numbers do not add because some states have more than one monitoring activity.

<sup>b</sup>Forty-seven state Medicaid programs reported having some children in fee-for-service arrangements in 1997.

<sup>c</sup>Forty-one state Medicaid programs reported having some children in managed care arrangements in 1997.

HRSA Reviews Have Not Identified Health Centers’ Lack of Adherence to Federal Policies

Health centers are expected to follow not only HCFA’s screening policy as set out in the Medicaid manual but also HRSA’s screening policy. HCFA requires screening for children 12 and 24 months old, while HRSA requires screening only at 12 months. HCFA’s requirements cover only children in Medicaid, while HRSA’s cover all children seen at the health centers,

<sup>31</sup>HCFA, State Medicaid Manual, Part 5—Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), Transmittal No. 12, Washington, D.C., Sept. 1998.

<sup>32</sup>In the survey, we specifically asked for activities that monitor capitated or prepaid providers. For clarity, we refer to these providers as “managed care” providers.



although these often include children in Medicaid.<sup>33</sup> Officials at one of the seven health centers we visited advised us that the center had screened virtually no children for lead poisoning and, thus, the center was not following either HCFA's or HRSA's policy of screening children at least once. At two other health centers, only one of the two policies was being followed:

- The Watsonville health center medical director told us that the center was relying on screening children at 12 months. While this paralleled HRSA policy, it was not consistent with the Medicaid policy requiring that screening services be provided to children at both 12 and 24 months.
- Officials at the San Antonio health center stated that they had a screening policy for children in Medicaid that was consistent with HCFA's. It had no policy for screening uninsured or other children visiting the center, as is required by HRSA.

Although HRSA monitors health centers' lead screening policies, it has not identified the discrepancies we found. HRSA conducts periodic reviews at health centers, and these reviews are supposed to assess whether the health center evaluates all children for lead poisoning risk, participates in lead poisoning prevention programs, and provides screening and testing services. Reviewers are instructed to look at medical records for the use of preventive health schedules and strategies for lead screening but are not required to assess actual lead screening practices or rates. None of the reviews for the centers we visited had reported the concerns with the lead screening policies and practices we identified in our review.

## Screening Rates Are Highest in States With Screening Requirements

Among the states we reviewed, the rate at which children were reportedly screened for blood lead levels was highest in states that had their own screening requirements. Such laws are relatively infrequent: According to CDC, among 20 states that CDC had surveyed, only 3 (Illinois, New York, and Rhode Island) have laws or administrative rules requiring screening. Among the seven states and localities we contacted, New York and Massachusetts had regulations that providers screen for blood lead levels. New York law requires that all children be screened at least at or around ages 1 and 2, and Massachusetts requires that at a minimum all children be screened annually through the age of 48 months. Both states also require

<sup>33</sup>In addition, health centers may provide health care for children enrolled in Head Start. Reviewing individual states' Head Start policies for requiring lead screening was outside our scope, but we did determine that federal Head Start policy differs from that of HCFA and HRSA in that it allows Head Start programs to set lead screening policies locally.



proof of lead screening as a condition for entering day care or kindergarten.<sup>34</sup>

The requirements and built-in enforcement mechanisms in the two states' laws appeared to make a difference in screening: Among the states and localities we visited, New York City and Massachusetts screened the highest proportion of children. The New York City Health Department reported that in 1996, 44 percent of 1- and 2-year-olds had been screened, and Massachusetts reported a 54-percent screening rate for children aged 1 through 5 for that year, compared with generally lower screening rates estimated by other programs we visited in states without screening laws.<sup>35</sup>

These observations are consistent with those of a CDC-contracted research study evaluating activities of CDC's Lead Poisoning Prevention Branch. One conclusion of the study was that the legal infrastructure is important but underdeveloped. Statutes and ordinances in screening, reporting, and treatment activities were not in place, or not enforced, in many surveyed sites.<sup>36</sup>

## Perceptions of the Problem's Seriousness Vary Greatly and Affect Decisions to Screen

The variation in screening rates that we found reflects the fact that lead poisoning is perceived as a significant problem in some places but not in others. Several health center officials indicated that a major barrier to screening is physicians' perceptions that lead exposure is not a problem in their communities. Supporting these views, a 1996 Academy of Pediatrics survey of 734 primary care pediatricians found that the most commonly reported reason the surveyed pediatricians did not screen was a reported low prevalence of elevated blood lead levels among their patients. Furthermore, only 38 percent of primary care pediatricians believed that the benefits of screening exceeded the costs.<sup>37</sup> The survey also found that not all providers agree with CDC's definition of the level of concern for lead

<sup>34</sup>Specifically, Massachusetts requires that for entry to kindergarten children present evidence of having been screened for lead poisoning. New York requires child care providers, public and private nursery schools, and preschools that are licensed, certified, or approved by any state or local agency to obtain a copy of a certificate of lead screening for every child who is at least 1 year old but younger than 6.

<sup>35</sup>While most of the programs we reviewed that were in places without screening laws (Georgia, Texas, and Washington and Philadelphia) did not know actual screening rates in the city or state, most had estimated screening for selected time periods and populations of children. See appendix VII for a further discussion of these estimates.

<sup>36</sup>Macro International, Inc., Executive Summary: Evaluation of Activities of the Lead Poisoning Prevention Branch, Contract 200-88-0641-18, Mar. 30, 1994.

<sup>37</sup>James Campbell and others, "Blood Lead Screening Practices Among US Pediatricians," *Pediatrics*, Sept. 1996, pp. 372-77.



toxicity. Seventy-three percent of pediatricians surveyed agreed that blood lead levels at or higher than 10 µg/dl should be considered elevated, but 16 percent disagreed.<sup>38</sup> Eighty-nine percent of primary care pediatricians believed that epidemiologic studies should be performed to determine which communities have high proportions of children who have elevated blood lead levels. The survey found that many pediatricians may want additional guidance about when to consider selective screening.

Similarly, a 1996 study produced for the Childhood Lead Poisoning Prevention Branch of the California Department of Health Services assessed providers' blood lead screening practices and attitudes and found that "Many physicians who care for children are not convinced that lead poisoning is a significant health issue for their patients."<sup>39</sup> The report concluded that physicians would be more likely to screen if they thought that the cost-benefit ratio of screening were more attractive. Frequently identified barriers to screening included a lack of solid local prevalence data, the absence of a quality screening questionnaire to identify risk, parent and physician resistance to venous blood draws, the absence of an effective medical treatment for identified cases lower than 45 µg/dl, and the lack of access to screening for some children who are at greatest risk for lead poisoning.<sup>40</sup>

The opinions of a state's medical establishment can have a profound effect upon the state's efforts to screen its at-risk population. For example, the Massachusetts health department reported that 3.7 percent of the children who had been screened had elevated blood lead levels, and the state has a policy of screening all children annually until the age of 48 months. In contrast, even though the Washington lead registry shows that 3 percent of children screened for lead in that state have elevated blood lead levels, providers there apparently regard 3 percent as evidence that elevated blood lead levels are not a major concern. In discussions with health department, Medicaid, and provider community officials, and in reviewing

<sup>38</sup>Another survey of 155 pediatricians found that only two-thirds knew the lowest blood lead level associated with deficits in cognition. See Susan Ferguson and Tracy Lieu, "Blood Lead Testing by Pediatricians: Practice, Attitudes, and Demographics," *American Journal of Public Health*, Vol. 87, No. 8 (Aug. 1997), pp. 1349-51.

<sup>39</sup>Duerr Evaluation Resources, *Final Report: Results of a Statewide Study of Physician Attitudes, Knowledge and Practices Related to Childhood Lead Poisoning* (Chico, Calif.: Department of Health Services, Childhood Lead Poisoning Prevention Branch, Nov. 1996).

<sup>40</sup>CDC supports the use of venipuncture (or venous) blood draws or a process called "fingerstick" as the sample-collection method, depending on the accuracy of the test results, the availability of trained personnel, convenience, and cost. In fingerstick sampling, a small amount of blood is collected from a puncture in a child's finger. According to CDC, if children's fingers are cleaned carefully, capillary (or fingerstick) sampling can perform well as a screening tool.



provider commentaries on lead screening in Washington, we learned that providers in the state often did not support testing for blood lead levels because lead poisoning is not viewed as a significant problem. However, a survey in high-risk areas in Washington found prevalences of blood lead levels greater than 10 µg/dl as high as 8.4 percent.

The influence of such views can be so strong that even children who seem to be at obvious risk of lead exposure might not be screened. We visited the health center in Everett, Washington, because of its location in a zip code with high numbers of pre-1950 houses and because it served relatively high numbers of children in Medicaid. However, we also learned that it was a few blocks from a state-designated Superfund site, a lead, gold, silver, and arsenic smelter at the turn of the century. Many soil samples taken in residential neighborhoods within the boundaries of the site had levels of lead contamination greater than the state-mandated cleanup level, and one sample exceeded the state level by nearly 40 times. Despite the fact that the health center served children living within the boundaries of this site, the medical director advised us that virtually none of the children were screened for elevated blood lead levels.<sup>41</sup> According to health center officials, the local health department had for years discouraged providers at the health center from screening for elevated blood lead levels because of the perception that there was not a problem in the area. However, we were advised that in response to our review, the health department provided the health center with guidance on screening children visiting or playing near the smelter site for elevated blood lead levels, as well as children living in older housing and with other risk factors.

To some extent, the legal infrastructure for lead screening and related activities is influenced by the perceptions of physicians and others about the extent to which lead exposure is a local problem. Although faced with the loss of federal grant money, some states have not passed laws or otherwise demonstrated that they have the legal authority and ability to support housing-related lead poisoning prevention activities (addressing training, certification, and accreditation programs for lead-based paint

<sup>41</sup>The Agency for Toxic Substances and Disease Registry (ATSDR) lists lead second in its ranking of dangerous contaminants. A 1992 ATSDR analysis paper reviewed several quantitative studies on the effect of lead-contaminated soil on children's blood lead levels and found a strong positive correlation between exposure to lead-contaminated soil and lead levels. ATSDR recommended that, at all sites, health assessors evaluate the need for follow-up activities. See Charles Xintaras, "Analysis Paper: Impact of Lead-Contaminated Soil on Public Health," HHS, Public Health Service, ATSDR, Atlanta, Georgia, May 1992, <http://atsdrl.atsdr.cdc.gov:8080/cxlead.html#head011000000000000> (retrieved 2/10/98 12:17:40).



professionals such as lead inspectors and abatement contractors).<sup>42</sup> While housing-related lead poisoning prevention programs were outside the scope of our review, since they do not directly address lead screening and medical treatment activities, states' legislative experiences provide insights about variations in the states' efforts and legal infrastructure. A 1998 report found that many states were unable to pass legislation in part because of (1) mixed messages from federal and state agencies and the medical community about the seriousness of the public health risk from lead and (2) a lack of compelling data at the state level to support legislation.<sup>43</sup>

Perceptions of the problem affect not only physicians' decisions to screen but also officials' views on monitoring the implementation of federal lead screening policies. For example, HRSA officials in several regions responsible for health center performance reviews (including lead screening and treatment) indicated to us that they did not believe lead poisoning was a concern in their regions. According to a HCFA official, a 1994 survey of 967 Medicaid-eligible children in Alaska has often been cited as evidence that federal screening policies are unreasonable and should not be enforced.<sup>44</sup> This survey, finding that less than 1 percent of Medicaid-eligible children had elevated blood lead levels, was the basis for a 1997 Council of State and Territorial Epidemiologists' position statement that screening should be state-specific and that HCFA should allow state (targeted screening) plans to include children enrolled in Medicaid.<sup>45</sup>

<sup>42</sup>Under section 404 of the Toxic Substances Control Act as added by the Housing and Community Development Act of 1992, states had until August 31, 1998, to implement a federally authorized program to administer lead poisoning prevention activities addressing training, certification, and accreditation programs for lead-based paint professions. One condition of federal authorization was to demonstrate that the state had the legal authority and ability to implement the program. Without an authorized program by August 31, 1998, states were subject to an EPA-administered and -enforced program and concomitant loss of federal grant money for the preempted state programs.

<sup>43</sup>Analysis of Lead (Pb) Hazard Reduction Legislation: Implications for Washington State (Olympia, Wash.: Washington State Department of Health, Apr. 1998). Other barriers cited included that the legislative climate was not conducive to passing any new legislation that might cost constituents money and concern about regulatory reform and the lack of funding or unfunded mandates.

<sup>44</sup>Laura Robin, Michael Beller, and John Middaugh, Childhood Lead Screening in Alaska: Results of a Survey of Blood Lead Levels Among Medicaid-Eligible Children (Anchorage: Alaska Dept. of Health and Social Services, Oct. 10, 1994).

<sup>45</sup>Council of State and Territorial Epidemiologists, 1997 CSTE Annual Meeting Position Statement EH-1 (Revision of Blood Lead Screening) (Montgomery, Ala: 1997), <http://www.cste.org/page61.html> (cited Oct. 29, 1997).



## Difficulties in Providing Preventive Care Services Keeps Screening Rates Low

Even states that have mandatory lead screening laws are not screening all children. To some extent, low rates of screening reflect another important factor: Many children are not receiving preventive health care in general through well-child visits. Health center and health department officials said that a significant barrier to higher screening rates is that many children do not receive preventive health care of any kind. Health center officials told us that it is difficult to convince parents of the importance of preventive care when their children are not sick and, as a result, many children visit their providers only when they are sick. To illustrate, health center officials at the center we visited in Texas told us that for every well-child visit, they provide more than 80 acute care visits.

Our studies and those conducted by others lend further support to the views we heard expressed. In a study examining the effects of health care insurance on access to care, we found that although having health insurance and a regular source of health care facilitates a family's use of health services, low family income and education levels, lack of transportation, and language differences are barriers to obtaining and appropriately using them.<sup>46</sup> A 1997 HCFA-supported study on the use of EPSDT and other preventive and curative services by children enrolled in Medicaid also found particular challenges in providing preventive health services.<sup>47</sup> Using 1992 Medicaid billing data from four states, the study found that only 54 percent of the children recommended for well-child visits (and, thus, preventive care) actually made such visits.

A related problem, health center officials said, is that in many cases at-risk children are not screened because parents do not ensure that their children receive the blood lead tests ordered by their physicians. Health officials and a California assessment of the issue indicated that because many clinics and physicians' offices prefer venous blood draws to obtain the blood sample and do not have a readily available pediatric phlebotomist (or blood-drawer) to conduct blood tests, children must be referred elsewhere for testing. Many of these children never arrive at the sometimes distant facilities they are referred to and consequently are not tested. The California Lead Poisoning Prevention Program identified the reasons the children do not receive tests as ordered as such things as parents' lack of transportation or child care for children who would

<sup>46</sup>Health Insurance: Coverage Leads to Increased Health Care Access for Children (GAO/HEHS-98-14, Nov. 1997).

<sup>47</sup>Norma Gavin and others, Comparative Study of the Use of EPSDT and Other Preventive and Curative Health Care Services by Children Enrolled in Medicaid: Final Project Synthesis Report (Research Triangle Park, N.C.: Research Triangle Institute, Apr. 1998.)



remain at home, difficulty in getting time off from work, and a lack of understanding of the test's importance.<sup>48</sup>

A new medical device may make lead tests easier to administer and perhaps reduce this problem. Our review of medical records at the health centers showed that typically physicians send blood samples to laboratories for analysis and may not receive the results for several days. If the results show that a child has an elevated blood lead level, another appointment must be scheduled to perform a confirmatory test or other follow-up, which may not be kept. In September 1997, the Food and Drug Administration approved the first hand-held screening device for testing blood lead levels. While providers must still obtain a blood sample through a fingerstick procedure, the device shows the lead level results immediately without the use of a laboratory. Although the hand-held device makes tests more convenient for providers, it complicates the gathering of data by state and local health departments. For the most part, states rely upon data from laboratories to assess their screening and prevalence rates. If blood tests are not sent to laboratories but instead are interpreted on the spot, states will need to identify an alternative means, such as representative surveys, for obtaining this information.

## Better Data on the Prevalence of Elevated Blood Lead Levels and Better Program Coordination Could Help Improve Screening

Two types of actions could help resolve the problems that health officials and others have identified. First, because most state Medicaid programs and health departments we contacted lack good data to assess the risk of lead poisoning in local communities, improved data collection might help them develop a better understanding of the degree to which portions of their communities' populations are significantly at risk. This is particularly important because the prevalence of elevated blood lead levels can vary even within a region or community. Second, further coordination between lead poisoning programs and programs addressing other preventive health care services could help identify models and avenues for identifying and targeting the at-risk population for lead screening. While the growth of managed care represents another opportunity to improve lead screening, recent research indicates that many states have yet to address lead screening responsibilities in managed care contracts.

<sup>48</sup>To help address this barrier, the Childhood Lead Poisoning Branch of the California Dept. of Health Services has developed a program to increase onsite blood lead testing by health care providers. See Guidance Manual for Implementing Fingerstick Sampling (Emeryville, Calif.: Childhood Lead Poisoning Prevention Branch, California Department of Health Services, Sept. 1997).



## Most Medicaid Programs and Many State Health Departments Lack the Data Needed to Assess Risk and Develop Targeted Screening Recommendations

Most state Medicaid programs and health departments we contacted lack representative, reliable data from which to assess true prevalence and, thus, risk. According to CDC, the best data available for developing state and local screening policies is actual population-based data about the prevalence of elevated blood lead levels—data that show the extent of elevated blood lead levels in children who represent the entire population. CDC guidelines state that “These data should be used to explain and support the recommendations to those who must carry them out, especially child health-care providers, medical groups, managed-care organizations, insurers, and parents.”

Responses to our survey show that most Medicaid programs lack prevalence information needed to best target screening and to document the absence of lead exposure within their population of children—specifically, data on the extent of screening and prevalence of elevated blood lead levels. In our survey of state Medicaid programs, we asked directors whether their states had all the information they needed to determine the extent of screening and the prevalence of elevated blood lead levels in the Medicaid population—including the number of children in Medicaid, the number of children in Medicaid who are screened for elevated blood lead levels, and the number of those who have been identified as having elevated blood lead levels. Directors in only 12 states responded that they could readily produce such data. Twenty-nine indicated that getting such data would be difficult.

Each of the seven CDC-supported lead poisoning prevention and surveillance programs we contacted indicated that their states have laws requiring laboratories or others to report certain results of blood lead tests. However, most of these laws are not comprehensive enough to ensure that a state can identify the extent of childhood blood lead screening and the true prevalence of elevated blood lead levels in children by local area. To do so, reporting all blood lead levels, including those not considered to be elevated, would be necessary, and a representative sample of children would have to be screened. Of the seven programs we reviewed, three were in states that had such universal reporting laws: Massachusetts, New York, and Washington. Only Massachusetts and New York had screened enough children to ensure that their prevalence data represented the population of children in the state. California, Georgia, Pennsylvania, and Texas required reporting of lead levels only if they were above a defined threshold; for example, California required laboratory



reporting only for levels of 25 µg/dl or higher.<sup>49</sup> CDC found, in assessing the reporting requirements of selected states and localities receiving CDC lead poisoning prevention and surveillance grants, that 10 of 20 grantees had laws or administrative rules requiring the reporting of all blood lead levels. A further discussion of CDC lead poisoning prevention programs appears in appendix IV.

Such data are important to have in targeting screening, since the prevalence of elevated blood lead levels varies widely even among communities within the same state or geographic area. For example, the Lead Poisoning Prevention Branch of the California Department of Health Services has compiled data from several studies reviewing the prevalence of elevated blood lead levels in various communities in the state and found prevalence rates ranging from less than 5 percent to more than 20 percent. The branch concluded that this variability reflects the complex structure of exposure sources and populations at risk in the state. A 1996 survey conducted by the Colorado Department of Public Health and Environment similarly shows the importance of local-level prevalence data for determining where to target screening. This survey assessed the prevalence of childhood elevated blood lead levels in north central Denver and found a prevalence rate much higher than expected. Specifically, 16.2 percent of the 173 participating children had elevated blood levels, more than five times the overall rate of 3.2 percent calculated from 1994 surveillance reports for Denver County, which encompasses Denver. The final report concluded that the findings were consistent with the idea that there exist "pockets" of childhood lead poisoning within the city.<sup>50</sup>

### Interventions to Improve Immunization Coverage Show Promise for Improving Lead Screening

HHS' interventions to overcome some barriers to providing preventive health services might serve as models and offer avenues for improving lead screening. Recent research has shown that the underimmunized population and the population most at risk for elevated blood lead levels are often the same. Specifically, a March 1998 study found that underimmunized children in inner cities are also at greater risk for anemia and elevated lead levels.<sup>51</sup> Another study found that children who were not

<sup>49</sup>Texas health department officials told us that although laboratories found it easier to report all lead levels rather than just those above 10 µg/dl, the legislature thought that requiring all results would be a burden.

<sup>50</sup>See Richard Hoffman and others, Denver Childhood Blood Lead Survey Final Report (Denver, Colo.: Colorado Dept. of Public Health and Environment, Jan. 1996).

<sup>51</sup>William Adams and others, "Anemia and Elevated Lead Levels in Underimmunized Inner-city Children," Pediatrics, Vol. 101, No. 3 (Mar. 1998), pp. 1-6.



up-to-date on their immunizations were likely not to be up-to-date for lead screening.<sup>52</sup>

HHS has found some avenues through its National Immunization Program to reach the at-risk population. The program seeks to increase immunization rates in the preschool population through grants to each state and 28 urban areas to implement immunization action plans. In 1995, we reported on promising strategies for increasing immunization, including provider-based strategies, such as assessing clinic immunizations and offering feedback or creating reminder and recall systems or registries to reduce missed opportunities for immunization.<sup>53</sup> For example, over the past several years, CDC has developed the Clinic Assessment Software Application to analyze providers' records and diagnose immunization problems at their sites. Providers and other clinic personnel are then given feedback on their immunization activities. CDC studies show this strategy to be highly effective in reducing missed opportunities and improving immunization rates among children receiving care at clinics, and a CDC immunization official told us that it may be feasible and reasonable to modify the software to add the ability to review lead screening. Such promising strategies also include improving immunization rates by coordinating immunization services with large public programs such as WIC. WIC is considered to be well suited to coordination with immunization services, in part because participants typically visit a program site with some regularity.<sup>54</sup> Since 1997, CDC has required grantees to employ such strategies as a condition of receiving immunization grant funding.<sup>55</sup> Further, since 1994, CDC has had in effect a

<sup>52</sup>Gerry Fairbrother and others, "Markers for Primary Care: Missed Opportunities to Immunize and Screen for Lead and Tuberculosis by Private Physicians Serving Large Numbers of Inner-city Medicaid-eligible Children," *Pediatrics*, Vol. 97, No. 6 (June 1996), pp. 785-90.

<sup>53</sup>See *Vaccines for Children: Reexamination of Program Goals and Implementation Needed to Ensure Vaccination* (GAO/PEMD-95-22, June 1995).

<sup>54</sup>Several studies have examined and reported on the benefits of various strategies linking immunization to WIC participation. See, for example, Shefer and Mize and also Guthrie Birkhead, Helen Cicirello, and John Talarico, "The Impact of WIC and AFDC in Screening and Delivering Childhood Immunizations," *Journal of Public Health Management Practice*, Vol. 2, No. 1 (1996), pp. 26-33.

<sup>55</sup>We reported in 1997 on states' efforts to assess pockets of children in need of immunization and their strengths and limitations. See *CDC's National Immunization Program: Methods Used to Identify Pockets of Underimmunized Children Not Evaluated* (GAO/HEHS-97-136R, Aug. 1997).



memorandum of understanding with USDA to emphasize the importance of immunizing children who receive WIC benefits.<sup>56</sup>

No similar agreement exists between CDC or HHS and USDA regarding lead screening and treatment efforts. According to a CDC Lead Poisoning Prevention Branch official and officials from two health departments we contacted, WIC program emphasis on lead screening has decreased rather than increased since a 1993 change in USDA policy regarding lead screening in WIC clinics. In particular, a change in CDC recommendations regarding allowable tests for conducting blood lead screening required a change in WIC policy. As a nutrition program, WIC is required to screen participants for iron deficiency anemia. Until 1991, when CDC lowered the threshold of concern for lead toxicity, a screening test commonly used to diagnose anemia—called the erythrocyte protoporphyrin (EP) test—was also considered adequate for identifying elevated blood lead levels. CDC's 1991 statement indicated that the EP test was not sensitive enough to identify elevated blood lead levels under the new threshold values. Until this change of policy, WIC had encouraged agencies to use the EP test for both anemia and lead screening, and many states relied on WIC programs as primary providers for lead screening services. Following CDC's 1991 change in policy, a 1993 WIC memorandum refocused WIC's role in the lead initiative from active participation in screening to the more limited role of coordinating with other local health programs such as EPSDT, establishing referral systems, providing information and counseling, and developing appropriate plans of nutritional care for children who are affected.<sup>57</sup>

### Medicaid Managed Care Offers Opportunities for Increasing Screening Rates but Many States Have Yet to Act

The shift to managed care could add barriers to preventive health services such as lead screening, since numerous concerns have been raised about the extent to which Medicaid contracts with managed care organizations contain specific EPSDT requirements. However, research is also finding that Medicaid managed care presents opportunities to increase access to prevention and early intervention services. State Medicaid agencies have increasingly turned to managed care to cut health care costs while ensuring health care access for Medicaid enrollees. From 1983 to 1996, Medicaid managed care enrollment grew from around 750,000 to 13 million. On the basis of reported numbers from state Medicaid programs, we estimate that nationally 42 percent of Medicaid recipients

<sup>56</sup>Beginning with the fiscal year 1996 appropriation, the Subcommittee on Labor, HHS, Education, and Related Agencies of the Senate Appropriations Committee has recommended in report language each year that CDC ensure that immunization grantees reserve 10 percent of funds for immunization assessment and referral services at WIC sites.

<sup>57</sup>See WIC policy memorandum 93-31.



under the age of 6 were enrolled in managed care plans as of June 30, 1997.<sup>58</sup>

Concern has been raised about the extent to which children enrolled in Medicaid managed care plans are receiving services in line with EPSDT requirements. In May 1997, HHS' Office of Inspector General reported that only 30 percent of the children 5 years old and younger who were enrolled in managed care plans received all EPSDT services specified in the state periodicity schedule. Nearly 50 percent of this group received no EPSDT services at all. The Inspector General recommended that HCFA (1) revise its EPSDT reporting requirements and data collection to emphasize the number of children who receive all their EPSDT screens in a timely fashion, (2) encourage states to actively notify managed care plans of enrollees due for EPSDT exams and follow-up if EPSDT services are not rendered shortly thereafter, (3) work with states to ensure timely managed care EPSDT reporting, and (4) emphasize to states the need to define and clarify EPSDT requirements in their Medicaid contracts with managed care plans. An Inspector General official indicated that HHS was taking appropriate steps to implement these recommendations and that the Office of the Inspector General was continuing its monitoring of the recommendations.

Recent research has shown that many Medicaid contracts with managed care organizations still do not address lead screening. In August 1998, the George Washington University Center for Health Policy Research reported on provisions on childhood lead poisoning prevention services in Medicaid managed care contract documents (for contracts in effect during 1997).<sup>59</sup> The center reported that only 20 of the 42 contract documents it reviewed contained language addressing managed care organization duties related to lead-related care, primarily screening. The center also reported that contract documents rarely identified lead-related services either with respect to quality assurance or as a specific reporting duty.

In contrast, this study and others have found that some states have used their managed care contracts to build in EPSDT performance measures at the outset. According to a recent survey, 21 of 31 states reviewed that have

<sup>58</sup>HCFA does not record data on the extent to which state Medicaid programs have children in this age group enrolled in managed care arrangements. We derived this estimate from the responses to our survey of state Medicaid directors, who reported on children under age 6 (1) in Medicaid managed care and (2) in total covered by Medicaid as of June 30, 1997.

<sup>59</sup>See Elizabeth Wehr and Sara Rosenbaum, Medicaid Managed Care Contracting for Childhood Lead Poisoning (Washington, D.C.: Center for Health Policy Research, School of Public Health and Health Services, George Washington University Medical Center, Aug. 31, 1998).



managed care programs include performance targets in their contracts.<sup>60</sup> Hence, the contracts are vehicles through which state Medicaid agencies can set specific reporting standards and require the providers to submit data to measure their performance. For example, Wisconsin has established performance goals in its managed care contracts, including specific goals for blood lead screening, and has required managed care organizations to report data to measure this performance. The state has set as a performance goal that managed care organizations have an 85-percent lead screening rate by 1999. Annually, the state reports performance comparisons for managed care and non-managed-care providers. The 1995 comparison report found that managed care enrollees under age 5 received more preventive care screens than those receiving fee-for-service care. Lead testing among managed care enrollees was almost twice as high as in the fee-for-service population (11.9 percent versus 6.9 percent). According to the George Washington University report, 11 of 42 contracts reviewed contained language establishing some type of quality or performance standards relating specifically to lead.

<sup>60</sup>See Rosenbach and Gavin, "Early and Periodic Screening, Diagnosis, and Treatment and Managed Care," *Annual Review of Public Health*, No. 19 (1998), pp. 507-25.



# Several Problems Hinder Timely Follow-Up Treatment and Other Services

Once children's elevated blood lead levels are identified, it is important that they receive follow-up services, which can be complex and resource intensive but according to experts are necessary to minimize adverse health effects. CDC's recommended follow-up services include periodic retesting to ensure that lead levels decline and, for children who have higher levels, clinical management, care coordination, and other services such as investigations to determine the source of lead exposure. CDC believes that data collected on the provision of follow-up services are not reliable and, therefore, the extent to which these services are provided to children who have elevated blood lead levels is largely unknown. Our work at health centers and health departments across the country showed gaps in the timeliness of follow-up testing and other services: Providers miss opportunities to perform more timely follow-up tests, children do not return to the health center, and parents do not comply with providers' orders to have tests conducted. Another key problem is that state Medicaid policies often do not support paying for services that CDC recommends for treating children who have elevated lead levels, and most programs lack formal arrangements with other health or housing agencies regarding the treatment of children who are enrolled in Medicaid and have elevated blood lead levels. Having established relationships between providers and health and other agencies may become even more important as increasing numbers of children are covered under Medicaid managed care.

## Recommended Follow-Up Services Can Be Complex and Resource Intensive

Public health experts consider follow-up testing and case management of children who have elevated blood lead levels to be important aspects of treatment, particularly to ensure that blood lead levels do not continue to rise. According to the American Academy of Pediatrics, the amount and duration of a child's exposure to lead are key factors in toxicity levels. Early detection and source control are therefore important to minimizing adverse consequences.<sup>61</sup> Follow-up care for children identified with elevated blood lead levels is considered uniquely multidisciplinary, requiring close coordination between a child's health care provider, local public health department, and others. CDC indicates that to treat children for elevated blood lead levels, the lead source must be identified and controlled. Identifying how a child has been exposed to lead and preventing recurring exposure can be complex and may involve many more parties than the child's health care provider. Because childhood lead exposure is likely to be associated with poor and deteriorating

<sup>61</sup>See the statement of the American Academy of Pediatrics, Committee on Environmental Health, "Screening for Elevated Blood Lead Levels," *Pediatrics*, Vol. 101, No. 6 (June 1998), pp. 1072-78.



communities, children who have elevated blood lead levels may also lack adequate housing, routine medical care, and good nutrition. CDC's recommended treatment approaches vary depending on a child's blood lead level:

- CDC's recommended follow-up for levels between 10 and 19  $\mu\text{g}/\text{dl}$ —the range in most children who have elevated blood lead levels—is generally to test at least every 3 to 4 months, make referrals for social services, educate families about lead, and possibly provide clinical management and environmental investigations if the elevation persists.<sup>62</sup>
- For children whose lead levels are 20  $\mu\text{g}/\text{dl}$  or higher, CDC indicates that it is critical to reduce a child's exposure to lead. It recommends care coordination and investigations to determine the source of lead. CDC also recommends clinical management, including a clinical evaluation of the child's medical history and history of housing and other environmental sources of exposure, the correction of nutrition problems, and a physical examination to identify language delay or other neurobehavioral or cognitive problems that should be referred to other appropriate programs. Children who have extremely high lead levels (45  $\mu\text{g}/\text{dl}$  or higher) may need drugs to help reduce the lead toxicity, a treatment known as chelation therapy.<sup>63</sup>

For children in need of comprehensive services, CDC recommends that a follow-up team address the complex and resource-intensive care required. The team should consist of the child's health care provider, a care coordinator, a community-health nurse or nurse adviser, an environmental health specialist, a social services liaison, and a housing specialist. Generally, the child's health care provider monitors the child's blood lead levels, provides the direct medical treatment such as chelation therapy, and addresses any other medical or developmental issues that may arise. The community-health nurse or nurse adviser visits the child's home, interviews the family about possible lead sources, educates the family about ways to reduce lead exposure, and links the family to other services. The environmental health specialist investigates the child's environment, testing paint and taking other samples as needed to find and eliminate the

<sup>62</sup>In its 1991 guidelines, CDC recommended that tests showing blood lead levels of 10  $\mu\text{g}/\text{dl}$  or higher should be repeated in 3 to 4 months or less, depending on the lead level—the higher the level, the more frequent the testing. In its 1997 guidelines, CDC recommended even more frequent follow-up testing (retesting at 1- to 2-month intervals until blood lead levels have declined, lead hazards have been removed, and there are no new exposures). CDC also recommends clinical management and environmental investigation when two consecutive blood levels at least 3 months apart measure 15  $\mu\text{g}/\text{dl}$ .

<sup>63</sup>In chelation therapy, drugs bind or chelate lead, thus reducing its acute toxicity.



source of poisoning. See appendix IV for further information on federal policies for treating children who have elevated blood lead levels.

The federal government has several other roles in lowering blood lead levels. Federal Medicaid law requires that state Medicaid programs cover any treatment or other medical assistance necessary to “correct or ameliorate” physical and mental illnesses and conditions discovered through an EPSDT screen. This law has been at issue in numerous lawsuits related to defining “medically necessary” care.<sup>64</sup> Determining what constitutes medical treatment for an environmentally caused condition can be difficult. HCFA has indicated that at a minimum investigations to determine the source of lead exposure are important in treating a child diagnosed with an elevated blood lead level. HCFA and HRSA policies governing state Medicaid and health center programs generally recommend that providers follow CDC’s recommendations.<sup>65</sup> CDC grants for lead poisoning prevention and surveillance (usually awarded to state and local health departments) entail responsibilities for tracking and ensuring follow-up care.

## National Data Are Lacking, but Health Centers and Health Departments Vary in Providing Timely Services

No national database exists for reliably determining the extent to which follow-up services are provided. CDC requires its grantees to report on the environmental inspection of the homes of children who have elevated blood lead levels and on medical case management activities such as the number of new cases identified, children treated with chelation therapy, and cases closed. CDC officials indicated that this information is often incomplete and inconsistent. As a result, they said, it is generally not useful to compare performance or draw generalizations about progress. CDC officials indicated that they were reevaluating the data requirements and planned to issue new requirements in 1999.

## Health Centers Vary in Follow-Up Testing

Our reviews at six health centers across the country showed differences in the extent to which providers conduct follow-up tests and the extent to which these are performed in line with CDC’s recommendations.<sup>66</sup> At all six centers, some children had no follow-up tests after the initial diagnosis of

<sup>64</sup>See National Health Law Program and Texas Rural Legal Aid, *Toward a Healthy Future—Early and Periodic Screening, Diagnosis, and Treatment for Poor Children* (Los Angeles, Calif.: Apr. 1995).

<sup>65</sup>HCFA leaves discretion to providers with reference to CDC’s guidelines. HRSA requires that health centers establish a protocol for following up abnormal results and indicates that health care providers may use their professional judgment with respect to CDC’s guidelines.

<sup>66</sup>We exclude Everett, Washington, because virtually no screening tests for lead were conducted there.



elevated blood lead levels. When we visited the centers in late 1997 and early 1998, 32 of the 102 children in our sample whose elevated blood lead levels had been identified in 1996 had not yet received any follow-up tests. Table 5.1 shows that the extent of sampled cases that did not receive follow-up tests ranged from 9 percent to 62 percent at the six health centers.<sup>67</sup>

**Table 5.1: Extent to Which Children Who Had Elevated Blood Lead Levels Did Not Receive Follow-Up Tests at Six Health Centers**

Health center site	Percent of children who had elevated blood lead levels and received no follow-up tests
Atlanta, Ga.	62
Brooklyn, N.Y.	13
New Bedford, Mass.	32
Philadelphia, Pa.	20
San Antonio, Tex.	25
Watsonville, Calif.	9

Almost half of the follow-up blood tests for the 102 children whose medical records we reviewed were not conducted within CDC's recommended time period.<sup>68</sup> The percentage of untimely follow-up testing at the six health centers ranged between 19 and 66 percent, as shown in table 5.2.

<sup>67</sup>Some state Medicaid agencies and other researchers have similarly examined follow-up testing and treatment. For example, a 1996 Minnesota review of Medicaid screening and follow-up activities found that 18.4 percent of children who had elevated blood lead levels had received no documented intervention.

<sup>68</sup>We reviewed the medical records of children who had elevated blood lead levels in 1996 to assess whether follow-up tests were performed with the frequency recommended in CDC's 1991 guidelines. We used the 1991 guidelines since the cases were drawn from a time period before CDC's November 1997 guidelines. Since some children did receive several follow-up tests, we based timeliness on the percentage of tests showing an elevated blood lead level that were followed by a subsequent test in the recommended time. We discuss our methodology and findings in appendix V.



Table 5.2: Percentage of Untimely  
Follow-Up Blood Lead Tests at Six  
Health Centers

Health center site	Percent of follow-up tests not conducted within CDC's recommended time periods <sup>a</sup>
Atlanta, Ga.	66
Brooklyn, N.Y.	19
New Bedford, Mass.	54
Philadelphia, Pa.	39
San Antonio, Tex.	48
Watsonville, Calif.	29

<sup>a</sup>While we looked for follow-up tests within 4 months of the elevated blood level test, we found that in 58 of the 70 situations in which a test had not been conducted within 4 months, the test had also not been conducted even after 6 months. See appendix V for information on the criteria used for evaluating the timeliness of follow-up tests.

The clinic in Everett, Washington, was largely not conducting lead screenings and thus had not identified any elevated blood lead levels for follow-up. According to the Washington State Department of Health lead registry, which contains all statewide blood lead test results, less than 40 percent of children who had blood lead levels between 10 and 19  $\mu\text{g}/\text{dl}$  in 1996 received timely follow-up testing. The department reported in June 1997 that about one-third of the tests conducted in the past year for children whose levels were 20  $\mu\text{g}/\text{dl}$  and higher were not followed up with subsequent retests. It is at these levels that CDC recommends more intensive follow-up, including clinical management and environmental investigations to determine the source of lead.

## Health Department Case Studies Show Variation in Tracking Children Who Have Elevated Blood Lead Levels

We evaluated certain cases to determine how CDC-supported lead poisoning prevention and surveillance programs tracked them and ensured that the children received needed services.<sup>69</sup> Specifically, for diagnoses of lead levels 20  $\mu\text{g}/\text{dl}$  or higher, we determined what the CDC-supported lead poisoning programs (managed by the state or local health department) reported on the services they provided to the

<sup>69</sup>Differences in services may to some extent reflect differences in the two types of CDC grant programs—for lead poisoning prevention and for surveillance—and their associated funding levels. While both types of grant applications are evaluated in part for plans or systems to help ensure the follow-up of children, a CDC official indicated that unlike prevention grants, surveillance grants have a funding limit of \$95,000 and usually do not support health education, public health nurses, or environmental personnel. Washington and Texas were receiving surveillance grants at the time of our review, and New York City and the states of California and Massachusetts were receiving prevention grant funding. Georgia was not receiving CDC funding at the time of our review, but it did receive prevention grant funding in 1996. Philadelphia was receiving some CDC funding through the Pennsylvania grant.



children.<sup>70</sup> While all but one of the state and local health departments had records of some of or all the cases we tracked, they varied widely in the extent to which they documented activities to ensure follow-up services. For example, for the three children in Brooklyn whose blood lead levels were 20 µg/dl or higher, the CDC-supported lead poisoning prevention program at the New York City Health Department documented significant activity in terms of home visits and environmental inspections and other action to address the identified lead hazards. In contrast, according to state and local health officials, the two children identified with levels of 20 µg/dl or higher in Atlanta were not reported to the state or local health departments for follow-up. We could find no evidence that any follow-up testing or other services were provided to these children. Table 5.3 details the results of our case studies at the seven health center sites.

**Table 5.3: Health Department Follow-Up and Monitoring Activities for Children Who Had Blood Lead Levels of 20 µg/dl or Higher**

Health center site	Case status
Atlanta, Ga.	The two cases of 20 µg/dl or higher were not recorded in the state lead registry of laboratory reports on elevated blood lead levels, despite state law requiring such information. Neither the state nor the local health department was aware of these two cases and thus no follow-up activities, including testing, had been conducted by either organization. After our visit, the health center reported the cases to the health department.
Brooklyn, N.Y.	The three cases were reported to the local health department, which made between three and six attempts to inspect each home for lead, successfully inspecting each home at least twice. In each case, the medical provider was contacted, an order to abate the lead was issued, and an inspector observed that the abatement was completed.
Everett, Wash.	We did not test the Washington state system for tracking cases since we did not take a sample at the health center there. However, state health department officials told us that the state conducted environmental investigations for all children whose blood lead levels were higher than 20 µg/dl because most local health departments, which had this responsibility, did not have adequate resources to do so. The state health department reported that in 1997 16 children were diagnosed with levels higher than 20 µg/dl and that as of August 1998 9 had received home investigations, the cases of 3 had been closed, and the remaining 4 had not received follow-up for unknown reasons.

(continued)

<sup>70</sup>Four or fewer children had blood lead levels of 20 µg/dl or higher in our samples at each health center location. We asked state and local health departments tracking cases for those health center locations to provide information from their systems on these cases, including the date of the first investigation of the child's home or environment to identify sources of lead, the number of visits to the home made by health officials such as public health nurses, the number of inspections of the home and other contacts, and whether any activities addressed the source of lead.



Health center site	Case status
New Bedford, Mass.	The state health department had records of all four cases in our sample and had conducted at least one home inspection in each case. The lead in one child's residence was abated, one child had moved, and two children's residences had no lead paint violations.
Philadelphia, Pa.	The local health department had records of all four cases in our sample and had records of environmental investigations in two of the four cases. For one of the other cases, the health department had no record of the laboratory tests that indicated a blood lead level high enough to trigger an environmental evaluation. In the other case, an investigation was attempted and four visits were attempted or letters were sent but the health department was unsuccessful in contacting the child, inspecting the home, or otherwise intervening.
San Antonio, Tex.	The state health department had records of all four children in our sample but did not maintain information on home visits or other follow-up activities apart from blood tests. The local health department indicated that, in one case, the child's home was visited and an environmental investigation was performed and reported to the provider and the parents. Since the local health department did not have records for the three other children in our sample, we could find no evidence of follow-up activities other than lead testing.
Watsonville, Calif.	The state health department had records for the two children whose lead levels were 20 µg/dl or higher. It contracted with and paid most local health departments to conduct case management of children diagnosed with elevated blood lead levels. The local health department records for both children showed at least three home visits, but because exposure sources could not be validated, activities to address the lead had not been conducted. Both children had visited or lived in Mexico and been exposed to potential lead sources such as candy and pottery.

Note: Appendix VII discusses differences in states' legal infrastructure for reporting elevated blood lead levels and for requiring lead abatement activities.

## Barriers to Ensuring That Children Who Have Elevated Blood Lead Levels Receive Timely Follow-Up

We identified numerous barriers to conducting timely follow-up testing and other services that CDC recommends. As with screening, key barriers include missed opportunities to perform follow-up tests when children return to a health center and losing children to follow-up because they do not return to the health center or because their parents do not comply with the provider's order for follow-up blood lead tests.



## Providers Miss Opportunities to Perform Follow-Up Tests

Many health center providers miss opportunities for timely follow-up tests when children return for other care. All the health centers we reviewed had written protocols for the providers to use in determining appropriate follow-up treatment, most of which recommended follow-up tests for children whose blood lead levels are 10 µg/dl or higher, at increasing frequency the higher the lead level. The follow-up tests could be scheduled in separate appointments or conducted in conjunction with other types of visits children made to the center. At six of the seven health centers, however, providers often did not perform tests within the recommended time periods even though the children visited a center for other care. (See table 5.4.)

**Table 5.4: Missed Opportunities to Provide Follow-Up Tests**

Health center site	Percent of late tests in which follow-up could have been done sooner
Atlanta, Ga.	42
Brooklyn, N.Y.	20
New Bedford, Mass.	47
Philadelphia, Pa.	27
San Antonio, Tex.	33
Watsonville, Calif.	25

## Children Do Not Return for Follow-Up Care

Health center officials told us that since the population they serve tends to be transient, children often do not return for services. Our review of the medical records supports this observation and the providers' concern that some follow-up issues are beyond their control. In 22 of the 102 cases reviewed, the children never returned after the elevated blood lead level was identified.

Another associated problem beyond the control of health care providers is that parents do not always comply with their orders for follow-up blood tests. As with screening tests, parents may be required, as they are in California, to take their children to another location for tests. In 12 of 102 cases we reviewed, we found that the provider ordered a blood test but that there was no indication the test was conducted.



## State Medicaid Programs Often Do Not Reimburse or Formally Coordinate Key Follow-Up Services

Medicaid law requires the states to cover treatment and other medical assistance necessary to correct or ameliorate conditions identified through EPSDT screening tests (such as elevated blood lead levels). However, our review indicates that the states are considering their coverage for certain treatment and follow-up services deemed important by CDC and HCFA as optional. In addition, most state Medicaid agencies lack formal agreements with health departments and other agencies involved in funding, tracking, and providing screening and treatment services. Such collaborations may be increasingly important as managed care arrangements cover increasing numbers of children in Medicaid, but recent research indicates that state Medicaid agencies have yet to consider the need for such collaborations in their managed care contracts.

## Fewer Than Half of State Medicaid Agencies Reimburse for Key Follow-Up Services

In our survey of 51 state Medicaid programs, we found that many lack policies to cover investigative services to determine the source of lead exposure or care coordination and case management to ensure that children who have elevated blood lead levels receive the social, environmental, and other services they need.<sup>71</sup> While all the programs except one cover follow-up testing by public or private laboratories or other entities, only 23 reimburse for investigative services to determine the source of lead exposure, and 20 reimburse for case management and care coordination. Only 14 states reported that the state Medicaid program reimburses for both.<sup>72</sup>

As with screening, part of the reason why state Medicaid programs are not following HCFA policy may be unclear EPSDT policies coupled with the difficulty of determining what are “medically necessary” treatment services for children with an environmentally caused condition. HCFA has in the past supported CDC’s position that investigative services are important to treating elevated blood lead levels but has not taken the

<sup>71</sup>These policies may also be affecting screening rates. Health officials in some locations indicated that children are not screened in part because of insufficient resources and mechanisms for addressing elevated blood lead level cases. A 1992 survey of state health officers conducted by the Association of State and Territorial Health Officials found that major reported barriers to screening were insufficient resources for environmental follow-up and abatement.

<sup>72</sup>In the absence of a state policy for covering such services, the state may still be obligated under Medicaid law to reimburse for treatments or other forms of medical assistance that providers deem necessary to address a child’s health condition. However, it may then be incumbent on beneficiaries and providers to seek payment for such services. According to the April 1995 report of the National Health Law Program and Texas Rural Legal Aid, states that have not previously covered a service in their state plan are likely to lack processes to handle requests for coverage and claims payment. According to this report, in these cases, the lack of an approval process often means that when a claim is submitted it will be handled by denying coverage for treatment or that providers do not submit claims for services in the first place.



position in regulations or policy that all states are expected to cover such services or case management specifically for lead-poisoned children. In line with CDC's recommendations, HCFA in a 1992 memorandum to regional offices indicated that locating the source of lead is an "integral part of the management and treatment of a child diagnosed with an elevated blood lead level." However, in this memo HCFA also indicated that investigation "may" be a covered Medicaid benefit, and other references in HCFA's Medicaid manual and memos use similar language in indicating that investigation "may" be a covered service.

As one of the few states where the Medicaid program covers lead investigations, case management, and other services for children who have elevated blood lead levels, California provides an example of a state health department that has worked to ensure that adequate resources are available and that responsibilities are coordinated for treating lead-poisoned children. The Childhood Lead Poisoning Prevention Branch of the California Department of Health Services helps provide for screening, care coordination, environmental investigation, and other services for California's at-risk children. The program is partly supported by fees assessed on industries that have contaminated the environment with lead. The program has also negotiated reimbursements for costs associated with case management activities for children in Medicaid who have elevated blood lead levels and contracts with local health departments to perform such activities. In addition to case management and environmental inspection, the program has arranged for state Medicaid coverage of medical nutrition therapy and outreach and interagency coordination of blood lead testing and follow-up services. Data from California's lead exposure surveillance system indicate that environmental investigations are performed in 95 percent of cases of lead-poisoned children.

### Few State Medicaid Agencies Report Formal Collaborations With Other Agencies

Another tool for helping ensure that services are provided is a formal agreement between the state Medicaid agency and the health departments, housing departments, or others with responsibilities for paying for and providing services to children who have elevated blood lead levels. In our survey, only ten state Medicaid programs reported having such arrangements by providing documentation of agreements. The 1994 evaluation of CDC's Lead Poisoning Prevention Branch found that although collaborative links to address the needs of children are essential for both policy and service delivery, few CDC grantees had been successful in



building such links.<sup>73</sup> How well applicants for CDC grants demonstrate collaboration with important partners such as state Medicaid programs to ensure that adequate services are provided to children who have elevated blood lead levels is only a small part of application evaluations.<sup>74</sup> Further, how or whether Medicaid agencies collaborate with CDC grantees or public health departments is not routinely reviewed.

Formal collaborations work well in Rhode Island. The state's health department and its Department of Human Services (which administers the Medicaid program) have a formal agreement regarding responsibilities for case management payments, and the departments were actively collaborating at the time of our review to develop "lead centers" to provide comprehensive services to the state's children diagnosed with lead poisoning. Initial proposals were that such centers would provide intensive case management, assist families with housing, conduct housing inspections, educate parents, offer education on proper cleaning techniques, and make referrals for coordinating all needed medical and nutrition services.

### Medicaid Managed Care Presents Challenges and Opportunities to Improve Treatment Services

Formal coordination between Medicaid and other agencies may become even more important as increasing numbers of children in Medicaid are covered by managed care arrangements, changing traditional health department and provider roles for ensuring treatment services. On the one hand, some health departments and others are concerned that many managed care organizations are not set up to handle the coordination of care that is expected as the major treatment for children who have elevated blood lead levels. On the other hand, the availability of a "medical home" for children in managed care arrangements may enhance the continuity of care and offer a network of providers not otherwise available or easily accessible.<sup>75</sup>

Recent research indicates that state Medicaid agencies have largely not considered how managed care organizations should coordinate with health departments and others in treating children who have elevated blood lead levels and other conditions. The 1998 study of Medicaid managed care contracts supported by CDC and conducted by the Center for Health Policy Research of the George Washington University Medical Center identified concerns about the extent to which managed care

<sup>73</sup>Macro International, Inc., Executive Summary.

<sup>74</sup>CDC indicated that it weighted collaboration more heavily in 1997 than in earlier years.

<sup>75</sup>See Rosenbach and Gavin.



contracts clarified expectations regarding the coordination of care. The center found that very few Medicaid contract documents addressed either medical follow-up for children for whom screening showed elevated blood lead levels or the integration of medical follow-up with public health agency activities to identify and reduce lead hazards in these children's homes. The study reported that while managed care is viewed as a means of providing a medical home for children in Medicaid and creating administrative systems for tracking and ensuring the provision of care, many states have yet to really grasp the potential of managed care to improve the quality of lead-related treatment services.<sup>76</sup>

Our visits to two programs known for model case management of children who have elevated blood lead levels also found evidence of changing roles:

- Officials at the Kennedy Krieger Institute in Baltimore, Maryland, told us that their program for treating children for elevated blood lead levels depends largely on Medicaid funding and had seen a decline of more than 50 percent in patient referrals in 1 year since the state had implemented managed care within its Medicaid population. Officials expressed concern that managed care organizations would attempt to address the treatment of lead-poisoned children on their own without adequate knowledge of its complexities.
- Officials at the Westchester County Health Department in New York indicated that since managed care had been implemented there in 1995, their role regarding children who have elevated blood lead levels had changed significantly. Before 1995, the county was the local entity responsible for case management for all lead-poisoned children. With the advent of managed care, the county both acts as a subcontractor of managed care plans—contracted to perform case management services—and oversees the performance of managed care plans' screening and treatment activities. Officials indicated that a major challenge was to determine the effect of Medicaid managed care on lead screening and case management. They said that they were developing methods of monitoring managed care organization activities to ensure that children who have elevated blood lead levels receive needed care.

<sup>76</sup>Wehr and Rosenbaum.



# Conclusions, Recommendations, and Agency Comments and Our Evaluation

## Conclusions

The past success in dramatically reducing the number of children who have elevated blood lead levels has created new challenges for addressing this public health problem. Despite low screening rates, the number has been reduced by eliminating lead sources in gasoline, food sources, and paint. Today, most children who have elevated blood lead levels have relatively low levels compared with levels in earlier years. However, research is increasingly showing that even low levels of lead present a significant cost to children's potential and to their families, educators, and society at large. Since most children who have elevated blood lead levels are likely to have no overt symptoms, lead poisoning is a silent problem whose solution depends on proactive efforts to identify it. Identifying the children among the millions who are considered to be at risk because they live in poverty or older homes requires the concerted effort of public health officials, providers, and parents. New information points to a need for more diligent state and federal program involvement to ensure that at-risk children are screened and treated. National data show that most of the 890,000 young children who are estimated to have elevated blood lead levels have not been screened for lead and remain undetected, and most of these children are served by federal health care programs.

The federal role has been to set policies and requirements for federally supported health financing and service delivery programs and to support lead poisoning surveillance and prevention through grant programs. However, these programs do not yet ensure that screening and follow-up occurs. State implementation of federal policies has been spotty, and low national screening rates even within federal health care programs requiring periodic screening services reflect barriers to screening and treating children. The services that children receive also vary widely across the country, depending partly on whether state Medicaid agencies cover services such as investigations to determine the source of lead exposure and whether states and localities have passed laws and established systems to ensure that necessary services are received. While variation between states' programs and screening rates may be warranted to the extent that the risk for elevated blood lead levels varies between states and even within a state, most states lack representative, reliable prevalence and screening data upon which to make good determinations of who should and should not be screened.

HHS has done little to monitor the provision of lead screening services to children in federal health care programs, and state Medicaid programs often do little to monitor providers' compliance with federal screening policies. Improving federal monitoring of state and providers' compliance



is one option for improving screening. However, the success of such efforts may be limited, if providers remain unconvinced that lead poisoning is a risk to the children they serve. Therefore, ensuring the availability of data to more conclusively establish the extent of the risk and to target limited resources is an important federal role.

Representative, reliable local data on the extent to which children have elevated blood lead levels would help providers identify them more cost effectively and would help convince parents and providers of the need to screen. Such data could also be used to give federally supported health care programs more flexibility in basing their screening policies on the best available local data on children at risk.

The biggest challenge to meeting the HHS goal of eliminating lead poisoning by 2011 may be coordinating the efforts of the many players that help address this environmental health condition. Coordination must start at the federal level with those who set federal lead screening and treatment policies. Although managed care may complicate coordination as traditional health care delivery roles change, it also offers the opportunity to ensure that children receive a wider range of preventive health and treatment services by providing the opportunity to clarify expectations about providers' performance in managed care contracts.

Lead screening could also increase if more at-risk children used preventive health care services and if interventions for improving access to various services were integrated. In recent years, the federal government has supported state development of interventions such as the use of WIC clinics to ensure that children are immunized and systems for assessing providers' immunization rates. These efforts could serve as models or avenues for increasing lead screening.

## Recommendations

To improve federal efforts to ensure that federal health care programs reach at-risk children in need of screening and treatment for elevated blood lead levels, we are making a number of recommendations. These recommendations would improve (1) the information at the state and local levels needed to better target screening efforts to those at highest risk, (2) enforcement and monitoring of federal screening and treatment policies, (3) state Medicaid contracts with managed care organizations, (4) the policies regarding services that children who have elevated blood lead levels should receive, and (5) the coordination between lead poisoning screening and treatment efforts and other preventive health care programs.



## Improving Information

To improve the awareness of providers and the public about the prevalence of elevated blood lead levels among young children in their communities and to enhance the effectiveness of targeted screening efforts, HCFA and CDC should work more closely with state Medicaid and CDC-supported programs to encourage information-sharing and the development of data needed to better identify at-risk children. Specifically,

- state Medicaid programs should be encouraged to work with state health departments to develop systems to identify the prevalence of elevated blood lead levels among children in Medicaid and
- CDC should require grant applicants to (1) demonstrate that they have, or have systems to obtain, representative, reliable data on the prevalence of elevated blood lead levels in their states or communities or to commit to conducting periodic surveys to obtain such data and (2) commit to developing mechanisms for distributing such information to the public and providers.

## Improving Screening Rates

To improve screening rates within federal health care programs, HCFA and HRSA should improve the monitoring of adherence to federal lead screening policies within the Medicaid and Health Center programs. Specifically,

- HCFA should require state Medicaid agencies to report on the lead screening services that are provided to children within the EPSDT program and to document progress in meeting lead screening performance goals. HCFA should require the states that do not meet expectations to develop plans for improving their performance.
- HRSA should use current monitoring mechanisms to better ensure that health centers follow all federal lead screening policies.
- HCFA and HRSA should develop a process for waiving universal lead screening requirements when state programs can demonstrate that they have representative and reliable data and data systems upon which to base local policies.

## Improving Managed Care Contracts

To ensure that state Medicaid agencies' managed care contracts clearly delineate appropriate lead screening and treatment responsibilities, HCFA and CDC should work together to provide guidance to state Medicaid agencies on including lead screening and treatment protocols in managed care contracts.



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## Improving Reimbursement for Services

To ensure that state Medicaid agencies more consistently provide for reimbursement for services for lead-poisoned children, HCFA should clarify in regulation or Medicaid policy the expectation that, in line with CDC recommendations, all state Medicaid agency EPSDT programs include reimbursements for investigations to determine the source of lead exposure and case management services for children identified with elevated blood lead levels. Further, HCFA should consult with CDC to delineate and clarify its expectations for the other services it deems medically necessary to treat children who have elevated blood lead levels.

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## Integrating Lead Screening With Other Preventive Health Care for Children

To improve the efficiency and effectiveness of lead screening and other preventive health care efforts and to marshal federal health care resources for reaching at-risk children, HHS should explore options for better coordinating interventions to improve lead screening with other preventive health services such as immunization. One such option HHS should consider would establish a formal agreement or requirements for coordinating HHS' lead screening and treatment activities with those of the WIC program.

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## Agency Comments and Our Evaluation

HHS commented on a draft of our report in a December 22, 1998, letter. HHS generally agreed with the recommendations of the report. HHS provided several technical comments, which were incorporated into our report as appropriate, and several clarifications and qualifications, which are discussed below. HHS' letter is printed in appendix VIII.

HHS agreed with our conclusion that managed care presents additional opportunities to improve Medicaid services for lead screening and treatment. However, HHS did not agree with our conclusion that the transition to managed care may also complicate efforts toward coordinating the many players needed to address lead poisoning, indicating that the report does not provide evidence of such a conclusion. As discussed in the report, our conclusion is based partly on the research conducted by George Washington University and others showing that states have frequently not acted on the opportunities that managed care presents to improve these services. Also as indicated in the report, it rests on information regarding the effect managed care is having on how health departments and other providers ensure that children who have elevated blood lead levels receive needed follow-up services. In considering HHS' comments, we have modified the report to distinguish between opportunities that are not yet acted upon and challenges faced by



changing roles in the delivery. HHS also suggested, and we concurred, that the title of the report should be modified to avoid the implication that CDC was the report's main focus in reaching at-risk children.

In regard to our recommendation that HHS develop better data on the prevalence of lead poisoning in particular geographic locations, HHS agreed that better prevalence data would be valuable. However, HHS also raised concerns about how this could be done, expressing concern about the use of the NHANES for this purpose and citing instead planned improvements to its surveillance system to ensure that consistent data are collected. We recognize the limitations of the NHANES for assessing prevalence within local areas and did not intend to suggest that it be used to assess local prevalence levels. We have modified our report accordingly. We continue to believe that until surveillance data can be shown to be reliable for particular states or areas, grantees should be required to commit to periodic surveys such as focal surveys of high-risk or other areas to gain data for areas of concern (suggested as an option by HHS in its comments).

HHS also agreed that better information on screening rates within federal health care programs is needed. HHS pointed out several reasons why developing screening rate information is problematic, including additional administrative burdens on state Medicaid agencies, but indicated that it is committed to working with its stakeholders to develop and improve data collection. HHS indicated that it would initiate appropriate actions to respond to the parts of our recommendation related to improving health center oversight and establishing a waiver process from universal screening requirements for states that can demonstrate low-prevalence communities.

HHS agreed with our remaining three recommendations concerning improving managed care contracts, reimbursement for services, and integration with other federal programs. In this regard, HHS cited several specific actions it had taken or planned to take. Specifically:

- CDC will continue to further develop, and HCFA will encourage states to use, model Medicaid managed care contract language to help ensure that high-risk children are screened and receive appropriate timely follow-up services.
- HCFA will clarify its policy to the states on requirements that all appropriate treatment coverable under Medicaid should be provided to children who have elevated blood lead levels.



- HHS has recently rechartered its CDC Advisory Committee on Childhood Lead Poisoning Prevention to include representatives from HCFA and HRSA, with working groups directed at addressing a number of issues in our report.

Because the report discusses the role of WIC in lead screening, we provided a copy of a draft of the report to USDA program officials for review. In commenting on the draft, the Associate Deputy for Special Nutrition Programs noted that although WIC does not have a specific legislative mandate for lead screening, it often conducted the lead screening test in conjunction with required anemia testing until CDC revised the protocols for measuring blood lead levels (calling for more sensitive and significantly more costly procedures than were used routinely in WIC). The Associate Deputy stated that although WIC remains committed to lead screening, it is not funded for blood testing beyond the general scope of an anemia test. The Associate Deputy also said that if new technology and protocols are developed that could permit lead screening without further appreciable cost or time beyond which WIC usually devotes to anemia screening, USDA would be pleased to work with CDC to determine the feasibility of using them in WIC clinics. USDA provided us with technical comments that we incorporated as appropriate.







# Methodology and Results of NHANES Data Analysis

The National Health and Nutrition Examination Survey (NHANES), conducted multiple times since 1960 by the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC), is designed to provide national estimates of the health and nutrition status of the noninstitutionalized civilian population of the United States aged 2 months and older. Our analysis was based on the NHANES data gathered during NHANES III, Phase 2, which was conducted from October 1991 through September 1994 and represents the most current information available.<sup>77</sup> Details of the survey design, questionnaires, and examination components are published in the NHANES III Plan and Operation reference manual.<sup>78</sup>

## The NHANES Sampling Process

The NHANES sample selection process, along with the weighing of participants, is designed to ensure that the sample is nationally representative of the U.S. civilian noninstitutionalized population 2 months of age and over. The selection of persons to participate in NHANES had four steps. First, the 13 largest counties were selected automatically and 68 other counties were selected randomly, yielding a total sample of 81 counties. Second, geographic areas were randomly selected within those counties. Third, households and certain other types of group quarters (such as dormitories) were selected within those areas to identify potential participants.<sup>79</sup> Fourth, specific individuals in selected households were identified on the basis of demographic characteristics. The National Center for Health Statistics has published the details of the survey design and weighing methods.<sup>80</sup>

## The Variables and Definitions We Used

Persons participating in NHANES were interviewed extensively and given a thorough physical examination in which a blood sample was taken. Data collected from the interviews, physical examinations, and blood samples

<sup>77</sup>The NHANES III survey had five goals: (1) estimate the national prevalence of selected diseases and risk factors, (2) estimate national population reference distributions of selected health characteristics, (3) document and investigate reasons for long-term trends in selected diseases and risk factors, (4) contribute to an understanding of disease origins and causes, and (5) investigate the natural history of selected diseases.

<sup>78</sup>National Center for Health Statistics, "Plan and Operation of the Third National Health and Nutrition Examination Survey, 1988-94," *Vital Health Statistics*, Vol. 1, No. 32 (1994).

<sup>79</sup>NHANES III oversampled selected subpopulations to increase the reliability of estimates. These subpopulations were children aged 2 months through 5 years, blacks, Mexican Americans, and persons 60 years old or older.

<sup>80</sup>"Weighing and Estimation Methodology Executive Summary," *National Health and Nutrition Examination Survey III* (Rockville, Md.: Westat, Inc., 1996).



varied with the participants' age. For our analysis, we used the blood lead levels derived from the blood samples for children aged 1 through 5. We also used specific information gathered during the interviews:

- health insurance status, including Medicaid status;
- household income;
- family participation in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); and
- previous tests for blood lead.

Of the 15,427 persons examined in NHANES III, Phase 2, the survey results for 2,350 children aged 1 through 5 years contained data on blood lead levels, health insurance status, WIC participation, and history of blood lead screenings.<sup>81</sup> We excluded from our analysis some children who may be eligible for federal health care programs in order to present conservative estimates of the prevalence of elevated blood lead levels. We excluded children whose income, insurance status, or WIC participation was unknown.

The variables and population estimates that we selected were consistent with those CDC used to estimate the prevalence of elevated blood lead levels among the population at large. CDC defined low-income persons as persons whose household income was 130 percent of the federally defined poverty level or less and old housing as housing built before 1946.<sup>82</sup>

## Data Reliability

We reviewed the NHANES design, data reliability checks, and reporting guidelines before using its data. We also compared the NHANES-computed estimates with Bureau of the Census population estimates, reports on the Medicaid population by the Health Care Financing Administration (HCFA), and Department of Agriculture (USDA) estimates on the WIC population. NHANES estimates for the number of children receiving Medicaid, low income and uninsured, or participating in WIC were generally consistent

<sup>81</sup>In some instances, the NHANES survey had information on some of these questions but not on others. When we used those questions in our analysis, we excluded the children whose survey results were missing.

<sup>82</sup>Our definition of the low-income population was consistent with CDC's but differed from that used by the Health Resources and Services Administration (HRSA). HRSA targets low-income populations whose income is 200 percent of the poverty level or less. We used CDC's more conservative definition of low income in order to maintain consistency with CDC's published reports on blood lead levels.



with estimates published by HCFA, the Bureau of the Census, and USDA.<sup>83</sup> On the basis of these reviews and comparisons, we concluded that the NHANES data were sufficiently reliable to meet our objectives.

## Analysis Results

The tables in this appendix show the estimates and their confidence intervals from the NHANES data. There is a 5-percent chance that the actual number is outside these limits.<sup>84</sup> While the comparatively small sample size of some subpopulation categories results in a relatively wide range between the high and low estimates, the numbers of children at the low ends of these estimates remain substantial.

A small number of the means and confidence intervals we present vary slightly from those we presented in our previous reports because of slight changes in estimation techniques and methods as suggested by a National Center for Health Statistics official.<sup>85</sup>

<sup>83</sup>The NHANES III, Phase 2, estimate for children in Medicaid aged 1 through 5 between 1991 and 1994 was 6,274,000. The HCFA estimate for fiscal year 1993 (the midpoint for NHANES III, Phase 2) was 6,632,000. The NHANES III, Phase 2, estimate for the number of low-income children aged 1 through 5 who did not have health insurance while participating in NHANES was 1,086,000. The Bureau of the Census 1993 estimate for the number of poor children aged 1 through 5 who did not have health insurance was 1,224,000. The NHANES III, Phase 2, estimate for children in WIC aged 1 through 4 years between 1991 and 1994 was 3,891,000. USDA's estimate for the number of children aged 1 through 4 in WIC as of April 1994 was 3,465,000. An undetermined portion of the difference between the NHANES and USDA estimates may stem from the nature of the WIC participation question in the NHANES survey, which requested information on the participant's status in the past month. The USDA estimate does fall within the 95-percent confidence interval for the NHANES estimate.

<sup>84</sup>Means, proportions, and standard errors were obtained by using Software for Survey Data Analysis (SUDAAN), as suggested in the NHANES III Analytic and Reporting Guidelines.

<sup>85</sup>Following a suggestion from a National Center for Health Statistics official, we used only the weight for children older than 1 who were examined away from home (only children who were younger than 1 year old were examined at home).



Appendix I  
Methodology and Results of NHANES Data  
Analysis

**Table I.1: Estimated Number of Children Aged 1 Through 5**

	Sample size	Mean	Estimate	
			Lower limit	Upper limit
All children <sup>a</sup>	2,744	20,183,000 <sup>b</sup>	16,895,000	23,472,000
Children in Medicaid	984	6,275,000	5,484,000	7,066,000
Low-income uninsured children	261	1,086,000	908,000	1,263,000
Children in WIC <sup>c</sup>	678	3,891,000	3,314,000	4,469,000
Other children <sup>d</sup>	1,014	11,947,000	11,119,000	12,774,000

<sup>a</sup>The sample analyzed was for all children regardless of whether federal health care program status and blood lead results were known. For other samples we analyzed, we excluded children whose survey results were missing responses to questions used in our analysis.

<sup>b</sup>CDC weighted the NHANES sample to approximate the Bureau of Census 1993 undercount-adjusted Current Population Survey.

<sup>c</sup>Children participating in WIC may also be participating in the Medicaid program or may have low incomes and no health insurance. These figures are for ages 1 through 4, since WIC is for children through age 4 only.

<sup>d</sup>Children who had health insurance and were not in Medicaid or WIC.

**Table I.2: Estimated Number of Children Aged 1 Through 5 Who Had Elevated Blood Lead Levels**

	Sample size	Mean	Estimate	
			Lower limit	Upper limit
All children	2,386	890,000	557,000	1,223,000
Children in Medicaid <sup>a</sup>	984	535,000	254,000	815,000
Low-income uninsured children <sup>a</sup>	261	67,000	1,000	145,000
Children in WIC <sup>a</sup>	678	452,000	262,000	642,000
Other children	1,014	202,000	107,000	297,000

Note: CDC defines elevated blood lead levels as 10 µg/dl or higher.

<sup>a</sup>Numbers may not add up because children can be eligible for more than one federal health program.

We performed separate analyses for children at ages 1 and 2. To provide conservative estimates of children not screened, we limited our analysis to children for whom the data indicated that they had an opportunity to receive a blood lead test that Medicaid paid for. Specifically, we limited our analysis to a cohort of children who (1) were in Medicaid for 6 months before and after their birthday, (2) had their first or second birthday between July 1994 and June 1996, (3) had made at least one visit to a Medicaid provider, (4) had no evidence of ever having been managed



**Appendix I  
Methodology and Results of NHANES Data  
Analysis**

**Table I.3: Estimated Number of  
Children Aged 1 Through 5 Screened  
for Elevated Blood Lead Levels**

	Sample size	Estimate		
		Mean	Lower limit	Upper limit
All children	2,350	2,319,000	1,750,000	2,888,000
Children in Medicaid <sup>a</sup>	966	1,183,000	862,000	1,504,000
Low-income uninsured children <sup>a</sup>	260	182,000	83,000	281,000
Children in WIC <sup>a</sup>	669	682,000	434,000	930,000
Other children	999	868,000	583,000	1,152,000

Note: CDC defines elevated blood lead levels as 10 µg/dl or higher.

<sup>a</sup>Numbers may not add up because children can be eligible for more than one federal health program.

**Table I.4: Estimated Number of  
Children Aged 1 Through 5 With  
Undetected Elevated Blood Lead  
Levels**

	Sample size	Estimate		
		Mean	Lower limit	Upper limit
All children	145	557,000	455,000	659,000
Children in Medicaid <sup>a</sup>	95	347,000	266,000	427,000
Low-income uninsured children <sup>a</sup>	12	19,000	1,000	36,000
Children in WIC <sup>a</sup>	68	301,000	223,000	378,000
Other children	27	120,000	55,000	186,000

Note: CDC defines elevated blood lead levels as 10 µg/dl or higher.

<sup>a</sup>Numbers may not add up because children can be eligible for more than one federal health program.

\*Survey design, weights, and standard errors were obtained by using Software for Survey Data Analysis (SUDAAN), as suggested in the NHANES III Analytic and Reporting Guidelines.

\*Questionnaire weights from a National Center for Health Statistics official, we used only the weights for children under age 1 who were contacted from their homes (only children who were younger than 1 were not made attempts at home).



# Methodology and Results of Medicaid Billing Data Analysis

To assess available data on state Medicaid screening for children covered by fee-for-service arrangements, we analyzed HCFA's State Medicaid Research Files. This database provides summarized information on Medicaid eligibility, claims, and utilization for states that participate in the Medicaid Statistical Information System. To facilitate research, HCFA has adjusted and reformatted the data and added service and eligibility codes. The data are arranged in five separate research files: Drug Claims, Inpatient Claims, Long-Term Care Claims, Other Ambulatory Claims, and Person Summary. Claims information is unavailable for children in Medicaid managed care arrangements, and reliable data on health care services provided to these children were not available at the time of our review.

## Analysis Methodology

We used the Person Summary and the Other Ambulatory Claims files to determine the percentage of children who had received a blood lead test within 6 months (on either side) of their first or second birthday. The Person Summary file contains characteristics such as birthday and dates of coverage for each person covered by Medicaid during the year. The Other Ambulatory Claims file contains records for medical services received.

Our analysis was limited to 1994 and 1995 data from 15 states, all states for which complete 1994 and 1995 data were available. We looked only at those 2 years because they were the latest years for which the State Medicaid Research Files data were available after HCFA's requirement for universal Medicaid screening went into effect in 1992. Thirty-one states did not provide data for 1994 and 1995. We dropped two states because we were able to access only part of the information we needed. We dropped three states because we were informed that at least one government laboratory did not bill Medicaid by individual children, making it impossible to determine from the billing data whether the children in those states had been given blood lead tests.

We performed separate analyses for children at ages 1 and 2. To provide conservative estimates of children not screened, we limited our analysis to children for whom the data indicated that they had an opportunity to receive a blood lead test that Medicaid paid for. Specifically, we limited our analysis to a cohort of children who (1) were in Medicaid for 6 months before and after their birthday, (2) had their first or second birthday between July 1994 and June 1995, (3) had made at least one visit to a Medicaid provider, (4) had no evidence of ever having been in managed



care, and (5) had no evidence of having had private health insurance before 19 months for 1-year-olds and 31 months for 2-year-olds.

To determine whether a child received a blood lead test, we reviewed outpatient claims for evidence of a laboratory procedure for blood lead analysis because that procedure is generally billed under a unique code and is easily identified. Provider services for drawing the blood sample, in contrast, could be bundled with other outpatient services and may not be readily identified. We credited a child as having received a blood lead test if a claim was made within 6 months of the child's first or second birthday. We checked with each participating state Medicaid program the particular coding and process they used for recording the state's data.

Other than these quality control checks, we did not independently verify the data in the State Medicaid Research Files because (1) HCFA's process for modifying the data includes quality control phases in which the data are analyzed with a number of statistical tools and crosswalks and (2) the data originated at the state level and the benefit of tracking them back to their source would not have outweighed the considerable cost and staff resources that this would have entailed. These data represent the most current and complete data available on state-level billing within Medicaid fee-for-service programs.

## Analysis Results

Our analysis shows that the rate at which 15 states' Medicaid fee-for-service programs provided blood lead screening for 1- and 2-year-old children in Medicaid was about 21 percent during 1994 and 1995. Rates for the 15 states ranged from less than 1 percent in Washington to about 46 percent in Alabama.<sup>86</sup> Table II.1 gives details of our results.

<sup>86</sup>We contacted both states' lead registries to determine whether these rates were consistent with the data they collected. Both health departments confirmed that these screening rates were consistent with those reported in their states. For example, less than 1 percent of all children in Washington were screened for lead poisoning in 1996.



Appendix II  
Methodology and Results of Medicaid Billing  
Data Analysis

Table II.1: Billing Rates of 15 State Medicaid Programs for Laboratory Tests for Blood Lead Levels in 1994-95

State	Age 1			Age 2			Total		
	Cohort size	Number screened	Percent screened	Cohort size	Number screened	Percent screened	Cohort size	Number screened	Percent screened
Alabama	16,800	8,331	50	15,073	6,210	41	31,873	14,541	46
Arkansas	5,200	1,556	30	5,606	2,001	36	10,806	3,557	33
Colorado	7,241	881	12	6,150	415	7	13,391	1,296	10
Delaware	1,600	612	38	1,495	324	22	3,095	936	30
Florida <sup>a</sup>	14,275	2,658	19	12,570	1,884	15	26,845	4,542	17
Kentucky	14,230	1,340	9	13,534	1,122	8	27,764	2,462	9
Mississippi	12,134	3,615	30	11,330	3,019	27	23,464	6,634	28
Missouri	20,947	4,216	20	19,329	3,246	17	40,276	7,462	19
Montana	1,809	44	2	1,762	61	3	3,571	105	3
New Jersey	14,585	6,144	42	14,759	5,424	37	29,344	11,568	39
North Dakota	1,268	34	3	1,312	41	3	2,580	75	3
Pennsylvania <sup>a</sup>	16,729	2,245	13	14,529	1,717	12	31,258	3,962	13
Vermont	1,267	120	9	1,309	78	6	2,576	198	8
Washington	17,331	61	0.4	15,251	22	0.1	32,582	83	0.3
Wisconsin	4,120	1,410	34	5,418	1,610	30	9,538	3,020	32
<b>Total</b>	<b>149,536</b>	<b>33,272</b>	<b>22</b>	<b>139,427</b>	<b>27,174</b>	<b>19</b>	<b>288,963</b>	<b>60,440</b>	<b>21</b>

<sup>a</sup>Excludes data from Pinellas County, Florida, and Philadelphia County, Pennsylvania, because laboratories in these counties do not send individual billing data to HCFA.



# Methodology for Our Questionnaire to Medicaid Directors

Lead Levels in 1994-95			
Total			
Percent screened	Number screened	Cohort size	Percent screened
46	14,841	31,873	47
38	12,887	33,808	38
10	1,388	13,991	7
30	908	3,008	23
17	4,542	26,848	10
8	2,482	31,164	8
28	8,034	28,864	27
10	7,482	67,318	17
3	108	3,811	0
38	11,288	29,744	37
8	78	2,582	3
13	2,982	21,588	12
8	188	2,878	8
0.0	88	22,882	0.1
32	3,038	9,038	30
21	8,048	38,048	18

We developed the questionnaire we sent to Medicaid directors to identify state Medicaid policies and practices for screening and treating children for elevated blood lead levels. We sought information on a number of items including (1) the program’s coverage of services for treating children with elevated blood lead levels, (2) the number of children in Medicaid aged 5 and younger in managed care arrangements, (3) the availability of data on screening and the prevalence of elevated blood lead levels in children in Medicaid, (4) monitoring mechanisms for ensuring that children in Medicaid are screened and treated once they have been identified as having elevated blood lead levels, and (5) documentation of EPSDT policies and other relevant information, such as formal agreements or memorandums of understandings with other agencies regarding screening or treatment of children for elevated blood lead levels.

We pretested the questionnaire with officials from several Medicaid agencies and obtained and incorporated comments from several reviewers knowledgeable about Medicaid or lead poisoning prevention programs. These reviewers included officials from HCFA, CDC’s Lead Poisoning Prevention Branch, and representatives of the American Public Welfare Association, the Academy of State Health Policy, and the Alliance to End Childhood Lead Poisoning.

We sent the final questionnaire to the Medicaid directors in 50 states and the District of Columbia in November 1997. All Medicaid directors or their representatives responded.

## Analysis Results

Of the 50 states and the District of Columbia, 15 states Medicaid fee-for-service programs provided blood lead screening for 1- and 2-year-old children in Medicaid. The screening rate was about 21 percent during 1994 and 1995. Rates for the 15 states ranged from less than 1 percent in Washington to about 46 percent in Alabama. Table II.1 gives details of our results.

We contacted health care providers to determine whether these rates were consistent with the data they collected. State health departments confirmed that these screening rates were consistent with those reported in their states. For example, less than 1 percent of all children in Washington were screened for lead poisoning in 1995.



# Federal Guidance and Policies for Screening and Treating Children for Elevated Blood Lead Levels

A number of federal health agencies play critical roles in providing national lead poisoning prevention guidance and policies. CDC issues recommendations for screening young children for elevated blood lead levels. HCFA, which administers Medicaid, establishes requirements for the provision of screening services for children covered by Medicaid as part of its EPSDT program. HRSA, which provides grants to health centers to provide health services in medically underserved areas—including services to children in Medicaid and uninsured children—establishes policies for children's health care services. Table IV.1 shows the specific guidelines and policies for screening established by these federal agencies.

**Table IV.1: Federal Guidance and Policies for Blood Lead Screening**

	Risk assessment	Screening	
		High risk	Low risk
1991 CDC guidelines	Assess the child's risk for high-dose exposure at 6 months and each regular office visit thereafter.	At a minimum, an initial test at 6 months and every 6 months thereafter (until two consecutive tests are lower than 10 µg/dl or three are less than 15 µg/dl, when testing can be reduced to annually). At 36-72 months, any child at high risk not previously tested should be tested.	At a minimum, an initial test at 12 months and rescreening at 24 months if possible.
1997 CDC guidelines	CDC recommends that state health officials develop screening guidelines. In their absence, CDC recommends screening all children at 1 and 2 years and 36-72 months who have not been previously screened. CDC recommends that, in general, children who receive Medicaid benefits should be screened unless reliable, representative blood lead level data demonstrate the absence of lead exposure.		

(continued)



**Appendix IV  
Federal Guidance and Policies for Screening  
and Treating Children for Elevated Blood  
Lead Levels**

	Risk assessment	Screening	
		High risk	Low risk
1994 HRSA Bureau of Primary Health Care policy for health centers	Assessment of risk should be a part of each well-child visit and other pediatric visits as appropriate, from 6 months to 6 years.	An initial test at 6 months or when the child is determined to be at high risk. Each center should develop a protocol for anticipatory guidance, risk assessment, lead testing, and follow-up of abnormal results.	An initial test at 12 months. Each center should develop a protocol for anticipatory guidance, risk assessment, lead testing, and follow-up of abnormal results.
1993 Medicaid manual	Beginning at 6 months and at each visit thereafter, the provider must assess the child's risk for exposure, asking specified questions at a minimum.	A test is required when a child is identified as being at high risk, beginning at 6 months. A test is required at every visit prescribed in the EPSDT periodicity schedule through 72 months, unless the child has already received a test within the last 6 months of the periodic visit.	A test at 12 and 24 months. A child between 24 and 72 months who has not been tested must be tested immediately.
1998 Medicaid manual	No risk assessment is required.	A screening test must be provided at 12 and 24 months. A child between 36 and 72 months who has not received a screening blood lead test must be screened.	A screening test must be provided at 12 and 24 months. A child between 36 and 72 months who has not received a screening blood lead test must be screened.

Ensuring that a child who has an elevated blood lead level receives the services needed to lower the level involves many organizations other than the child's health care provider. The CDC guidelines state that comprehensive services for a lead-poisoned child are best provided by a team that includes the health care provider, care coordinator, community-health nurse or nurse adviser, environmental specialist, social services liaison, and housing specialist. Drug remedies are generally not recommended except in chelation therapy for children who have blood lead levels of 45 µg/dl or higher.<sup>87</sup> Table IV.2 summarizes federal guidelines and policies for retesting to ensure that blood lead levels decline.

<sup>87</sup>Ongoing research by the National Institute of Environmental Health Sciences is assessing the treatment of children exposed to lead—specifically, home cleanup, nutritional supplementation, and chelation therapy for children whose blood lead levels are between 20 and 44 µg/dl.



**Appendix IV  
Federal Guidance and Policies for Screening  
and Treating Children for Elevated Blood  
Lead Levels**

**Table IV.2: Federal Guidance and Policies for Blood Lead Treatment**

	Recommendation
1991 CDC guidelines	At 10 µg/dl or higher, retesting at least at 3- or 4-month intervals until blood lead levels have declined. At 20 µg/dl or higher, CDC recommends clinical management—clinical evaluation for complications of lead poisoning, family lead education and referrals, chelation therapy if appropriate, and follow-up testing at appropriate intervals. At both levels, children should receive environmental investigation, coordination of care, and lead-hazard control services.
1997 CDC guidelines	At 10 µg/dl or higher, retesting at 2- to 3-month intervals until blood lead levels have declined, lead hazards have been removed, and there is no new exposure. At or above 20 µg/dl, retesting should be even more frequent. Recommendations for clinical management are the same as in the 1991 guidelines.
1994 HRSA Bureau of Primary Health Care policy for health centers	Each center should develop a protocol for anticipatory guidance, risk assessment, lead testing, and follow-up of abnormal results. All follow-up should be done in accordance with CDC guidelines.
1993 Medicaid manual	At 10 µg/dl or higher, providers are to use their professional judgment with reference to CDC guidelines covering patient management and treatment, including follow-up blood tests and investigations to determine the source of lead when indicated. <sup>a</sup>
1998 Medicaid manual	Adds to the 1993 manual that determining the source of lead may be reimbursable by Medicaid under certain circumstances but that reimbursement is limited to a health professional's time and activities during an on-site investigation of a child's home or primary residence. The child must be diagnosed as having an elevated blood lead level. Medicaid reimbursement is not available for any testing of substances such as water and paint that are sent to a laboratory for analysis.

<sup>a</sup>The manual is silent on expectations for covering treatment services but policy memorandums to regional offices state that investigations are integral to management and treatment and may be reimbursable under Medicaid as a rehabilitative services benefit.



# Methodology and Results of Screening of Children at Health Centers

## Sampling Methodology

To better understand the extent to which health centers screened children for elevated blood lead levels, we visited several high-risk centers and reviewed a sample of medical records. We considered a center to be at high risk if it was in an area with a large number of old (pre-1950) homes and saw a large number of children who were enrolled in Medicaid. We used 1990 census data to determine the number of old homes in the same zip code as a health center.<sup>88</sup> We used HRSA's 1996 Unified Data System Report data to determine the number of children who were younger than 5 and enrolled in Medicaid and seen at the center. For each of 10 HHS regions, we weighted these two parameters and ranked the health centers by their overall score. We then judgmentally selected one center from the five highest-risk centers in regions 1, 2, 3, 4, 6, 9, and 10. We limited our review to facilities in these seven regions because of time and resource constraints. We chose these locations to ensure that our samples were geographically diverse.

At six of the seven centers, we looked at the medical records for a random sample of about 15 children who were born between January 1, 1994, and June 30, 1995, and seen in 1996. These children were 1 or 2 years old in 1996. In considering whether children were appropriately screened, we presumed that as their regular provider, the health centers should have tested them. For this reason, we reviewed only medical records for children who had been seen at least once for a well-child (or preventive health care) visit or at least three times for acute care visits. We did not review any medical files at the community health center we visited in Everett, Washington. Officials there told us that they did not have records of screening any children in 1996 and had screened only three children in 1997. We confirmed with the Washington health department's lead registry that this center had screened three children during 1993-98.

## Analysis Methodology

At each health center, we reviewed health center protocols for screening children for elevated blood lead levels, when available, and discussed the protocols with the health center's medical director and other staff. We discussed with health center management and clinical officials the barriers they faced in ensuring that children seen at the health center were screened.

From each medical record we reviewed, we recorded data on each visit to the health center, including all dates representing screening blood tests.

<sup>88</sup>Wessex, Inc., publishes Pro/Filer, a data software combination product that allows users to access demographics from the 1990 U.S. census. We used pre-1950 housing age data because that was the closest breakdown to the pre-1946 cutoff used in our NHANES analysis.



We considered that a child had been screened if the medical record showed evidence of one blood lead test at some time in the child's history with the health center. We considered a screen to be in line with CDC recommendations and HCFA policy for screening at 1 year and 2 years if the child was screened within 6 months of his or her first and second birthday. If a child younger than 6 months was screened, we also considered this to be a screen at 1 year of age. We considered a screen to be on time if a child was screened at age 1 year and 2 (when presenting for care at those ages). We recorded evidence of a provider's order for a laboratory test as well as evidence of whether the laboratory test was actually performed in order to assess whether ordered tests were completed.

We conducted our medical records reviews at health centers from October 1997 through March 1998 in accordance with generally accepted government auditing standards.

## Analysis Results

Table IV.1 shows the results of our analysis. While we generally reviewed about 15 files at each location, at one we reviewed only 14 files and at another we reviewed 16 files. This slight variance in the sample size has no effect on the analysis because we are not projecting the results to a larger universe.

**Table V.1: Screening for 1- and 2-Year-Old Children at Seven Health Centers in 1996**

Health center site	Sample cases	Percent ever screened	Percent screened at age 1	Percent screened at age 2	Percent screened on time
Atlanta, Ga.	14	64	42	60	38
Brooklyn, N.Y.	15	93	80	64	60
Everett, Wash.	0	0	0	0	0
New Bedford, Mass.	15	100	100	85	85
Philadelphia, Pa.	15	100	100	85	87
San Antonio, Tex.	16	50	62	21	27
Watsonville, Calif.	15	80	46	54	27



# Methodology and Results for Follow-Up Testing of Children With Elevated Blood Lead Levels Seen at Health Centers

## Sampling Methodology

To better understand the extent to which health centers provided follow-up testing to children they found to have elevated blood lead levels, we visited several high-risk health centers and reviewed a sample of the medical records of these children. We considered a center to be at high risk if it was located in an area with a large number of old (pre-1950) homes and saw a large number of children who were enrolled in Medicaid. We used 1990 census data to determine the number of old homes in the same zip code as a health center.<sup>89</sup> We used HRSA's 1996 Unified Data System Report data to determine the number of children who were younger than 5 and enrolled in Medicaid and seen at the center. For each of the 10 HHS regions, we weighted these two parameters and ranked the health centers by their overall score. We then judgmentally selected one center from the five highest-risk centers in regions 1, 2, 3, 4, 6, 9, and 10. We limited our review to facilities in these seven regions because of time and resource constraints. We chose these locations to ensure that our samples were geographically diverse.

At six of the seven centers, we looked at medical records for a random sample of about 15 children who were found to have blood lead levels of 10 µg/dl or higher in 1996. We did not review any medical records at the health center in Everett, Washington. Officials there told us that they did not have records of screening any children in 1996 and, therefore, had not identified any children with elevated blood lead levels.

## Analysis Methodology

At each health center, we reviewed health center protocols for screening children for elevated blood lead levels, when available, and discussed the protocols with the health center's medical director and other staff. We discussed with health center management and clinical officials the barriers they faced in ensuring that children seen at the health center received follow-up testing and other services needed to lower their levels.

From each medical record we reviewed, we recorded data on each visit to the health center. We recorded all dates where records showed that a child's provider ordered a follow-up test, whether laboratory test results were present showing that the ordered test had been completed, and the blood lead levels. For each blood lead test result at 10 µg/dl or higher in the child's medical record for 1996, we determined the time until a follow-up test was done and the number of missed opportunities to follow up (when the child was given care but was not provided a follow-up blood lead test). For analysis purposes, we considered each blood test

<sup>89</sup>See the preceding footnote.



subsequent to one finding an elevated blood lead level to be a follow-up test, regardless of the time between tests.

For each elevated blood lead level, we determined whether a follow-up test was done on time, using criteria based on CDC's 1991 lead screening and treatment guidelines.<sup>90</sup> The specific criteria we used follow:

1. For children younger than 3, a follow-up should be done in 3 to 4 months (120 days or less).
2. For children 3 or older with a blood lead level equal to or greater than 15 µg/dl, a follow-up should be done in 3 to 4 months.
3. For children 3 or older with a blood lead level less than 15 µg/dl but a former blood lead level equal to or greater than 15 µg/dl, a follow-up should be done in 12 months.
4. Children aged 3 or older who have never had a blood lead level equal to or greater than 15 µg/dl do not need a follow-up.

We defined a missed opportunity as any visit to the center 90 days after the elevated blood lead level was found for children meeting criteria 1 and 2 above or 270 days later for children meeting criterion 3. Children with no follow-up and no missed opportunities were children who did not return to the center.

We conducted our medical records reviews at health centers from October 1997 through March 1998 in accordance with generally accepted government auditing standards.

## Analysis Results

Although our samples were randomly selected, it is not possible to project from our analysis. First, the sites were judgmentally selected from high-risk locations and thus are not representative of all health centers. Second, our analysis was not weighted to ensure that the samples reflected the population of children visiting the health centers. Table VI.1 shows our results.

<sup>90</sup>CDC's 1997 guidelines shortened the recommended time between follow-up tests.



**Appendix VI**  
**Methodology and Results for Follow-Up**  
**Testing of Children With Elevated Blood**  
**Lead Levels Seen at Health Centers**

**Table VI.1: Follow-Up Testing Provided to Children Whose Elevated Blood Lead Levels Were Identified by Seven Health Centers in 1996**

Health center site	Sample cases	Elevated blood level tests	Follow-up not on time	
			Number	Percent
Atlanta, Ga.	26	29	19	66
Brooklyn, N.Y.	15	27	5	19
Everett, Wash.	0	0	0	0
New Bedford, Mass.	19	35	19	54
Philadelphia, Pa.	15	28	11	39
San Antonio, Tex.	16	25	12	48
Watsonville, Calif.	11	14	4	29



# State Requirements Supporting CDC Grantees' Efforts to Ensure That Children Are Screened and Provided Follow-Up Services

In 1988, the Congress passed section 317A of the Public Health Service Act, authorizing CDC to make grants aimed at preventing childhood lead poisoning. The legislation established program goals that included screening infants and children for lead and follow-up referrals for treatment and environmental intervention for those found to have elevated blood lead levels. Two types of grants are available: Childhood Lead Poisoning Prevention grants and Childhood Blood Lead Surveillance grants. The majority of CDC's grant funding for childhood lead poisoning prevention—totaling \$27 million in fiscal year 1998—is directed toward prevention grants to (1) ensure that children are screened for lead poisoning, (2) ensure that children who have elevated blood lead levels receive timely and appropriate follow-up, (3) provide education about childhood lead poisoning and prevention, and (4) as of the fiscal year 1998 grant cycle, capture data on screening and follow-up activities for surveillance purposes. The surveillance grants are aimed as of the fiscal year 1998 grant cycle at developing statewide surveillance systems for capturing data on screening and follow-up activities and monitoring progress. Both grant types require a commitment to screening and reporting on elevated blood lead levels. In 1998, 43 state and local health departments received prevention grants and 10 received surveillance grants.

## Methodology

To determine what CDC-supported programs were doing to ensure that children were screened for elevated blood lead levels and, once identified, treated appropriately, we met with officials from six state and local Childhood Lead Poisoning Prevention and Childhood Blood Lead Surveillance programs. The prevention programs were managed by California and Massachusetts and New York and Philadelphia, and the surveillance programs were run by Washington and Texas.<sup>91</sup> We chose these programs because they were geographically close to the health centers that we visited. Although we did not meet with officials from the Georgia program, which was not receiving CDC grant funding at the time of our review, we did discuss the program with an official on the telephone. For each program, we obtained the most recent CDC grant application; state legislation or procedures addressing lead poisoning screening, reporting, and follow-up requirements; quarterly reports to CDC; available measures or estimates of screening and prevalence rates; and information about program activities.

<sup>91</sup>Philadelphia did not receive a CDC grant but received CDC funding through a CDC grant to Pennsylvania.



## State and Local Infrastructures for Ensuring Screening and Treatment Vary Widely

The legal infrastructure for lead poisoning prevention efforts at the state and local levels can significantly affect the ability of health departments to ensure the screening, reporting, and follow-up of children who have elevated blood lead levels. All the states and cities we contacted had some type of requirement for laboratories to report lead test results, but the reportable levels differed, affecting the usefulness of the data for identifying screening rates and areas with children at higher risk. Two of the seven programs we reviewed were in states that had requirements for screening, and those programs reported higher screening rates than the others we visited. More than half of the programs we contacted were in states lacking specific laws to enforce the abatement of identified lead hazards.

## Background on CDC's 1997 Screening Recommendations

Before 1997, CDC recommended that virtually all children aged 1 through 5 be screened for elevated blood lead levels. In November 1997, CDC acknowledged the generally low rates of screening and the declining prevalence of elevated blood lead levels and recommended that state public health officials develop statewide plans for childhood blood lead screening. CDC recommended that statewide plans contain if necessary different recommendations for screening within particular areas of a state and that targeted screening be based on data that are representative of the populations within those divisions. CDC set the following criteria for the states to use in evaluating the usefulness of blood lead level data and developing targeted screening plans: (1) laboratory data are available for children who have been screened, are of good quality, and are available for individual children; (2) demographic, socioeconomic, and geographic data are available for individual children; (3) screening data are representative of the pediatric population of the jurisdiction and are available for a sample that is large enough to allow a valid estimate of prevalence.

Policies based on such data are ideal because, while CDC's most recent estimate indicates that 4.4 percent of children aged 1 through 5 have elevated blood lead levels, their prevalence can vary significantly depending on local conditions. Lacking representative prevalence data, states and localities must rely on other sources such as census data to identify children who have universal risk factors. Such factors include living in older houses or in low-income families, and a significant number of young children have at least one risk factor.



## Provider Screening and Laboratory Reporting Requirements

Some states require providers to screen children and have mechanisms to ensure that screening occurs, such as requiring proof of screening as a condition for enrolling in daycare or school. CDC's 1998 assessment found that 3 of 20 states receiving CDC grants mandated screening all children aged 6 or younger. New York and Massachusetts, two of the seven CDC-supported programs that we contacted, had requirements that providers screen for blood lead levels. They also had the highest reported screening rates of the programs we visited.<sup>92</sup> Table VII.1 details differences in state screening and reporting policies and known or estimated screening and prevalence rates.

Many states and jurisdictions have laboratory reporting requirements to ensure that blood lead test results are reported. However, not all require the reporting of all (elevated and nonelevated) blood lead test results, limiting the usefulness of the data for targeting screening and surveillance purposes. Among the states and localities we contacted, universal reporting—the reporting of all blood lead level tests regardless of result—was required in Massachusetts, New York, and Washington. While Washington had universal reporting requirements and could calculate screening rates, less than 1 percent of the children there had been screened, preventing the state from accurately determining local prevalence levels. California, Georgia, Pennsylvania, and Texas required that only blood lead levels above a specific level be reported, hindering states and localities from reliably calculating their screening rates and prevalence levels. Instead, they relied on estimating general screening rates for population segments—for example, by reviewing Medicaid billing data.

CDC-provided information also shows how the states' requirements differ. A 1998 CDC assessment of selected grantees' laboratory reporting requirements found that, of 20 states contacted, 10 had legal requirements for laboratories to report all blood lead test results, 4 required reporting results of 10 µg/dl or higher, 1 required reporting results of 11 µg/dl or higher, 2 required reporting results of 15 µg/dl or higher, 1 required reporting results of 20 µg/dl or higher, 1 required reporting results of 25 µg/dl or higher, and 1 had no reporting requirements.<sup>93</sup>

<sup>92</sup>Although other states lacked reliable data on the screening rates, most had estimated rates based on other available information.

<sup>93</sup>CDC collected this information in its effort to report on state lead surveillance activities.



**Appendix VII**  
**State Requirements Supporting CDC**  
**Grantees' Efforts to Ensure That Children**  
**Are Screened and Provided Follow-Up**  
**Services**

**Table VII.1: 1996 Screening and Reporting Policies and Reported Screening Rates and Prevalence for Sites We Visited**

Site	Screening of certain children required by law	Health department estimates of screening rates for children aged 1 through 5	Level at which reporting is required by law (µg/dl) <sup>a</sup>	Reported prevalence of elevated blood lead levels
California	No <sup>b</sup>	Unknown (estimated 22 percent among children in Medicaid in 1994)	25	Unknown
Georgia	No	Unknown	10	Unknown
Massachusetts	Yes <sup>c</sup>	54 percent	0	3.7 percent
New York <sup>d</sup>	Yes <sup>e</sup>	44 percent for 1- and 2-year-olds and 42 percent for 3- to 5-year-olds	0	5.46 percent in 1995
Pennsylvania <sup>d</sup>	No	Unknown (estimated 30 percent in Philadelphia)	25 <sup>f</sup>	Unknown
Texas	No	Unknown (estimated 33 percent among children in Medicaid and 11 percent for all children)	10	Unknown
Washington	No	Less than 1 percent	0	Unknown <sup>g</sup>

(Table notes on next page)



Appendix VII  
State Requirements Supporting CDC  
Grantees' Efforts to Ensure That Children  
Are Screened and Provided Follow-Up  
Services

<sup>a</sup>California: Cal. Health and Safety Code, Sec. 124130 (Deering 1997); Georgia: Rules of the Department of Human Resources, Ch. 290-5-3; Massachusetts: Mass. Regs. Code tit. 105, § 460.070 (1995); New York: N.Y. Public Health, ch. 45, article 13, title Y § 1370-e(3); Pennsylvania: 28 Pa. Code, § 27.4 (1993); Texas: 25 Tex. Admin. Code § 37.334 (1998); Washington: Wash. Admin. Code § 246-100-042 (1997). The states verified these legal references in November 1998.

<sup>b</sup>Pursuant to a settlement agreement in federal district court, California adopted a blood lead screening protocol for its Child Health and Disability Prevention program based on CDC guidelines. Under the protocol, eligible children are to be screened at 1 and 2 years or between 25 and 72 months if not already screened and whenever a risk assessment identifies them as being at high risk.

<sup>c</sup>All children at approximately 1, 2, 3, and 4 years, with more frequent screening for children determined to be at high risk for lead poisoning after an assessment based on CDC guidelines. Blood lead screens are required for kindergarten enrollment.

<sup>d</sup>Screening and prevalence data for New York and Pennsylvania are those reported for the cities of New York and Philadelphia.

<sup>e</sup>All children at around 1 and 2 years, with screening of older children up to age 6 who are determined by a risk assessment to be at high risk. Blood lead screens are required for certified daycare and preschool enrollment.

<sup>f</sup>According to city health officials, blood lead levels equal to or higher than 15 µg/dl are required to be reported in Philadelphia.

<sup>g</sup>While reporting all blood lead test results is required, data are not considered to be representative since less than 1 percent of children have been screened.

## Requirements for Addressing Identified Lead Hazards

One barrier to screening that officials cited was the lack of authority or resources to address the sources of blood lead level conditions, often the lead hazards in housing. The National Conference of State Legislatures in 1997 compiled some information on residential abatement standards by state and reported that of 31 states for which information was available, only 11 required residential abatements. We found major differences in the authority of state and local officials to ensure that identified lead hazards are addressed, as shown in table VII.2.



**Appendix VII**  
**State Requirements Supporting CDC**  
**Grantees' Efforts to Ensure That Children**  
**Are Screened and Provided Follow-Up**  
**Services**

**Table VII.2: Seven Sites' Requirements  
for Addressing Lead Hazards in  
Housing**

Site	Requirement
California	Officials indicated that lead hazards could be considered a "nuisance" under the Health and Safety Code and that the health department could order an abatement of such nuisances under penalty of law. <sup>a</sup>
Georgia	No abatement laws.
Massachusetts	Responsible parties are required to abate lead hazards. Residences occupied by children who have blood lead levels of 25 µg/dl or higher must have environmental investigations. If an occupant refuses admission, a search warrant may be obtained. Owners of dwellings containing dangerous levels of lead in accessible structural material are required to obtain certification of full compliance or interim control where children younger than 6 reside or the owner receives an order to "delead." Owners may be liable for all damages to children caused by failure to comply with certain inspection and abatement requirements.
New York City	Responsible parties can be ordered to do lead abatement work. <sup>b</sup> If owners or other persons having legal responsibility fail to comply with an abatement order within 5 days, the city may contract for abatement at the owners' expense. <sup>c</sup>
Philadelphia	Owners of residential property are required to eliminate lead hazards caused by paint on threat of having their rental licenses revoked. <sup>d</sup> However, since only about 30 percent of landlords are licensed, according to city officials, such threats are not very effective.
Texas	No abatement laws.
Washington	No abatement laws.

<sup>a</sup>We did not address the extent to which other states had similar "nuisance" laws.

<sup>b</sup>Mass. Gen. Laws, ch. 111, §§ 194, 199 (1994); Mass. Regs. code tit. 105, §§ 460.020, 460.100.

<sup>c</sup>N.Y.C. Health Code, § 173.13.

<sup>d</sup>Philadelphia Health Code, § 6-403(5).



# Comments From HHS



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

DEC 22 1998

Ms. Bernice Steinhardt  
Director, Health Services Quality  
and Public Health Issues  
United States General  
Accounting Office  
Washington, D.C. 20548

Dear Ms. Steinhardt:

Enclosed are the Department's comments on your draft report entitled, "Lead Poisoning: Federal Health Programs Are Not Effectively Reaching At-Risk Children." The comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department appreciates the opportunity to comment on this draft report before its publication.

Sincerely,

*Michael Mangano*  
for June Gibbs Brown  
Inspector General

The Office of Inspector General (OIG) is transmitting the Department's response to this draft report in our capacity as the Department's designated focal point and coordinator for General Accounting Office reports. The OIG has not conducted an independent assessment of these comments and therefore expresses no opinion on them.



Comments of the Department of Health and Human Services  
on the General Accounting Office Draft Report,  
“Lead Poisoning: Federal Health Programs Are Not  
Effectively Reaching At-Risk Children”

The Department appreciates the increased emphasis that Congress has placed on the issue of lead poisoning, and welcomes the visibility that this General Accounting Office (GAO) report will give to the Department of Health and Human Services' efforts surrounding childhood lead poisoning screening and treatment. The Department shares GAO's concerns over this serious issue, and is committed to protecting the health and safety of our Nation's children. However, the Department would like to note that in order to effectively address childhood lead poisoning, there remain several challenges, including the need to improve data collection and analysis efforts, blood lead screening reporting requirements, and managed care contracts. The Department looks forward to working with Congress, GAO, the States, and others as we move forward to meet these challenges and protect the health of our Nation's children.

GENERAL COMMENTS

The focus of this draft report is on three Federal health care subsidy programs: Medicaid, a joint Federal/State program administered by the Department's Health Care Financing Administration (HCFA); the Health Center Program, administered by the Department's Health Resources and Services Administration (HRSA); and the Supplemental Nutrition Program for Women, Infants and Children (WIC), administered by the United States Department of Agriculture. The Department's Centers for Disease Control and Prevention (CDC) role in fulfilling its mission is multifaceted and includes assisting State and local childhood lead poisoning prevention programs, providing a scientific basis for policy decisions, implementing prevention methods, and facilitating the integration of health issues in policies established by housing and environmental agencies at the Federal, State, and local levels.

The CDC is committed to coordinating its efforts with Federal health care subsidy programs to eliminate childhood lead poisoning as a major public health problem by the year 2010. To this end, CDC provides grants, technical assistance, and consultation to State and local health departments for the development of childhood lead poisoning prevention programs and statewide surveillance of blood lead levels for children. As a condition of their grant programs, every State and local health department receiving grant funds is required to develop and implement a screening plan, based on CDC's new screening guidelines issued in November 1997, that will improve screening efforts. In the new guidelines (1997), CDC has stated that childhood lead poisoning is not uniformly



distributed throughout the Nation, and that State and local lead poisoning prevention programs must focus on children at highest risk; this will inevitably lead to much greater emphasis on screening socioeconomically deprived children, and is consistent with the GAO draft report's finding that as many as three-fourths of children with childhood lead poisoning are in this group.

Similarly, HCFA is committed to ensuring that eligible children receive the full set of health services, including blood lead screening, to which they are entitled under the Medicaid program as part of the Early and Periodic Screening Diagnosis and Treatment (EPSDT) services. We intend to reaffirm our commitment by working closely with other appropriate Federal agencies, the States, and the community in raising awareness of the importance of this issue and the requirements of the Medicaid program.

**OVERALL DEPARTMENTAL COMMENTS ON LEAD SCREENING AND  
MANAGED CARE**

Since the title of the report, "Lead Poisoning: Federal Health Programs Are Not Effectively Reaching At-Risk Children", inappropriately implies that CDC is a focus of GAO's report, the Department suggests that the title be changed to read "Lead Poisoning: Federal Health Care Subsidy Programs Are Not Effectively Reaching At-Risk Children".

On page 62, the report states that managed care may complicate efforts toward Federal coordination to address lead screening, due to changing traditional roles.

The report does not provide evidence supporting this conclusion. In fact, one State with a statewide managed care program is proactively involving their managed care organizations in a coordinated State effort to identify and treat lead poisoning.

Page 30 of the report also suggests that Medicaid managed care may create additional opportunities to improve lead screening, but this opportunity is lost because States have not included lead screening in their managed care contracts.

The Department is increasingly seeing specific language regarding lead screening in State managed care contracts. Often such language describes in detail lead poisoning indicators providers must use to determine the necessity of screening and outlines those instances when screens must be performed, as well as follow-up guidelines.

In addition, as noted on page 33, a high percentage of States with Medicaid managed care (26 of 41, or 63%) conduct some type of monitoring for lead screening. The fee-for-service monitoring percentage was slightly lower (22 of 47 or 46%). Therefore, under managed care programs, it may be easier for States to hold providers accountable for



Now on page 33.

providing such services, thus making the monitoring activity more effective.

Page 30 of the report states that at the State level many Medicaid programs conduct little or no monitoring to determine if children are being screened.

Now on pages 44-45.

The Department would like to note (and the report also notes elsewhere) that under Medicaid managed care programs States are beginning to use performance-based contracting as a tool to evaluate managed care plans. Often these performance measures include measures like lead screening or immunizations (as referenced in the report on page 42). The increased use of this type of tool may encourage States to incorporate a lead screening measure as a monitoring and performance evaluation tool.

As noted previously, monitoring efforts under managed care programs may be more effective due to enhanced provider accountability.

Now on pages 46-48.

On pages 43 through 45 the report states that the shift to managed care could "...create added barriers to providing preventive health services such as lead screening,...." but then adds that research is actually finding that managed care increases the opportunities for prevention and early intervention services.

The Department would like to underscore the finding that managed care does indeed increase opportunities for preventive and early intervention services. Unlike fee-for-service, managed care provides Medicaid beneficiaries with a constant, reliable source for medical care, a medical home. This medical home includes a primary care provider that is guaranteed to accept the Medicaid patient and will provide a constant source of care, contributing to continuity of care. When beneficiaries access one source for care the chances greatly increase that they will receive preventive services, such as lead screening.

Now on page 47.

Page 44 of the report indicates that a high percentage of children in Medicaid managed care are not receiving all EPSDT services, according to an Inspector General report.

The Department would also like the report to highlight its comment that States are actively taking steps to ensure EPSDT compliance under managed care, and one tool is the use of performance-based contracting, as mentioned earlier. This is very important. Indeed, as more States set specific EPSDT targets for managed care plans, it is likely that as compliance rates increase it will boost lead screening rates as well.



## **DEPARTMENT COMMENTS ON SPECIFIC RECOMMENDATIONS**

### **IMPROVING INFORMATION**

#### **GAO Recommendation #1**

To improve provider and public awareness of the prevalence of elevated blood lead levels among young children in their communities and enhance the effectiveness of targeted screening efforts, the Administrator of HCFA and the Director of CDC should work more closely with state Medicaid and CDC-supported programs to encourage information-sharing and the development of data needed to better identify at-risk children. Specifically:

- (1) As a condition of CDC grant funding, CDC should require applicants to (1) demonstrate that they have representative, reliable data on the prevalence of elevated blood lead levels in their states or communities, or commit to conducting periodic surveys to obtain such data, and (2) commit to developing mechanisms for distributing such information to the public and providers; and
- (2) State Medicaid programs should be encouraged to work with health departments to develop systems to identify the prevalence of elevated blood lead levels among Medicaid children in the state.

#### **Department Comment**

Regarding item (1), the report cites a problem in collecting reliable data on the prevalence of elevated blood lead levels at the State and local level and recommends that CDC require applicants to demonstrate that they have such data or commit to conducting periodic surveys to obtain such data. The report indicates that the prototype for conducting such periodic surveys is the National Health and Nutrition Examination Surveys III (NHANES III) at the national level. On a lesser level, States could conduct focal surveys in selected high-risk or other areas to gain data for areas of concern.

The Department agrees that such studies may be valuable and will continue to work with States to consider ways to promote and support their use at State and local health departments. However, the Department has concerns about utilizing the NHANES data. These data, while indeed a source of information about the prevalence of elevated lead levels in the population of the United States as a whole, do not permit valid estimates to be made for most geographic subsets of the total database. In addition, these data are not in a format that allows monitoring of short-term trends, calculation of incidence rates, examination of medical treatment or risk factors among children with elevated blood lead



levels, or identification of case clusters.

The CDC is actively moving towards improving its surveillance systems. Data requested for the surveillance component of the National Childhood Lead Poisoning Prevention program includes information on follow-up tests and environmental investigations. The CDC, in conjunction with the States, decided on collection of a set of core variables which include patient data, follow-up data, health care provider information, and laboratory/sample data.

These data are intended for use by Federal and State agencies to: 1) estimate the number of children with elevated blood lead levels, 2) monitor short-term trends, 3) identify clusters, 4) determine geographic distribution of cases, 5) examine risk factors among children with elevated blood lead levels, and identify risk factors for elevated blood lead levels among specific population groups, 6) target intervention programs for groups at risk for elevated blood lead levels, and 7) track national progress in eliminating childhood lead poisoning.

In response to the need for better data at the local level, in 1998, CDC included in its grant program announcements a mechanism for States to receive funds to conduct prevalence surveys. As surveillance activities expand, the data will reflect the existing distribution of lead poisoning more accurately.

The Department agrees with item (2) of the GAO recommendation regarding coordination of systems. The CDC has had a long-standing history of working directly with and through its grantee programs with State Medicaid agencies to encourage information sharing and help ensure the development of data needed to better identify at-risk children and develop information systems that characterize the problem. In addition, the Department will work more closely with State and local health departments to develop complete and reliable databases.

In response to CDC's November 1997 revised screening guidelines, HCFA encouraged State Medicaid agencies, in a letter dated April 13, 1998, to play an active role in the development of statewide screening. The HCFA also reiterated this in a presentation at the Medicaid/Maternal and Child Health Technical Advisory Group meeting in September 1998. In light of the GAO report, HCFA will again communicate in writing with the State Medicaid agencies and encourage their cooperation with health departments in an effort to educate providers and identify the prevalence of elevated blood lead levels among Medicaid children. The HCFA will also work with States to determine what best practices exist in the area, and HCFA will distribute this information to States. Furthermore, the CDC has also been strongly encouraging its grantees to integrate lead screening activities with other preventive health care programs for children,



as recommended in GAO's report. Some States, for example Rhode Island, are already coordinating their lead screening activities with their immunizations.

### IMPROVING SCREENING RATES

#### GAO Recommendation #2

To improve screening rates within federal health programs, HCFA and HRSA should improve monitoring of compliance with federal lead screening policies within the Medicaid and Health Center programs. To this end, the following steps should be considered:

- (1) State Medicaid agencies should be required to report on lead screening services provided to Medicaid children within the EPSDT program and to document progress in meeting lead screening performance goals. States not meeting expectations should be required to develop plans for improving performance.
- (2) For health centers, monitoring mechanisms currently in place (known as the Primary Care Effectiveness Reviews) should be better utilized to ensure all federal lead screening policies are followed.
- (3) To encourage states to develop better data and data systems, HCFA and HRSA should develop a process for waiving universal lead screening requirements when state programs can demonstrate that adequate (representative and reliable) data and data systems are available upon which to base such local policies.

#### Department Comment

The Department agrees that more information is needed on lead screening. However, the need to collect this data should be balanced against any increased burden on States and public health departments. Before beginning any new data collection effort, there should be agreement among the Department and other stakeholders that the effort is capable of producing meaningful results. Also, the collection effort should be well-developed, and it should be worth the time and resources expended.

Blood lead screening is a mandatory component of a periodic screening required as part of EPSDT services. However, there is no current statutory requirement for States to report specifically on blood screening. The statute has very clear requirements regarding the data that must be collected for EPSDT purposes: (1) the number of children provided health screening services; (2) the number of children referred for corrective treatment; (3) the number of children receiving dental services; and (4) the State's results in attaining



the participation goals set for the State. States are required to report annually on the provision of complete EPSDT screenings on the form HCFA-416. We had previously assumed that if a screening was reported on the HCFA-416 for children ages 1 and 2, that a blood lead screening test had been performed as part of that process. However, based on information in a GAO report to the Department in February 1998 and the information contained in this draft GAO report, it is apparent that this required screening is not taking place at an adequate level.

The HCFA is currently in the process of revising the HCFA-416, and a Federal Register notice of the changes to the HCFA-416 was published on October 28, 1998. The HCFA had considered adding a separate line requiring States to report the number of children ages 1 and 2 who received blood lead screening tests. However, a survey by a State Medicaid representative in Massachusetts confirms the following information in the GAO report. In some States, the public health department provides the lead screening tests and Medicaid is not billed for these tests. Because not all State Medicaid agencies are billed for blood lead screening tests, the data HCFA would collect on this separate line may be inconsistent and may misrepresent the actual testing in some States. It would not be possible for Medicaid to accurately report the number of children screened without this billing information.

Given the fact that simply adding a line to the HCFA-416 would not produce a meaningful or accurate picture of this issue, HCFA decided not to add such a line. This information is not currently included in any other data States report to HCFA. Nevertheless, HCFA recognizes that this is a significant issue that requires cooperation among many stakeholders and Federal agencies, including HCFA, CDC and HRSA, in order to collect and link appropriate data. The Department is committed to working with our stakeholders to address this issue and to develop and improve data collection.

In response to item (2), the Department agrees with this recommendation and will initiate appropriate actions as necessary after further internal discussions.

The third part of this recommendation states that HCFA and HRSA should develop a process for waiving universal lead screening requirements in States where data supports this action. The HCFA has been considering this option after receiving requests from two State Medicaid agencies for such a waiver. Although work is still preliminary, HCFA will begin to formally discuss this option with CDC and HRSA. The HCFA believes that, in order to waive universal screening in some States which have adequate data to support a claim that lead poisoning is not a significant problem for the Medicaid population in the State, there should be specific criteria or a process in place to assure that States continue to use targeted screening for children at high risk for lead poisoning.



## **IMPROVING MANAGED CARE CONTRACTS**

### **GAO Recommendation #3**

To ensure state Medicaid agencies' managed care contracts clearly delineate appropriate lead screening and treatment responsibilities, the Administrator of HCFA and Director of CDC should work together to provide guidance to state Medicaid agencies on including lead screening and treatment protocols in managed care contracts.

### **Department Comment**

The Department agrees with the recommendation that HCFA and CDC should encourage States to include specific language addressing lead screening in their managed care contracts. Many States are already using the George Washington University report on managed care contracts as a means of specifying State expectations of a managed care organization. The HCFA will continue to encourage the use of the George Washington University contract language in communications with the State Medicaid agencies.

In addition, as noted in the report, many States are turning to performance-based contracting as a means of understanding and monitoring the provision of preventive services, such as lead screening.

It also should be noted that CDC, through a contract with George Washington University, has been working to further develop model Medicaid managed care contract language (purchasing specifications) to help assure that high-risk children are screened and receive appropriate and timely follow-up services. This information will be shared with State and local health departments and State Medicaid agencies to ensure that responsibilities are clearly delineated in all managed care contracts.

## **IMPROVING REIMBURSEMENTS FOR SERVICES**

### **GAO Recommendation #4**

To ensure state Medicaid agencies more consistently provide for reimbursements for services to lead poisoned children, the Administrator of HCFA should clarify in regulation or Medicaid policy the expectations that, in line with CDC recommendations, all state Medicaid agency EPSDT programs include reimbursements for investigations to determine the source of lead and case management services for children identified with elevated blood lead levels. Further, HCFA should work closely with CDC to delineate and clarify its expectations for other services it deems as medically necessary to treat a child with an elevated blood lead level.



Department Comment

We agree with this recommendation, and it is consistent with recent departmental actions. Part 5 of HCFA's State Medicaid Manual, which was revised in September of 1998 to reflect the Department's new lead screening policy, includes language that investigations to determine the source of lead may be reimbursed under Medicaid if certain requirements are met. The HCFA defines what is reimbursable as being "...limited to a health professional's time and activities during an on-site investigation of a child's home (or primary residence). The child must be diagnosed as having an elevated blood lead level. Medicaid reimbursement is not available for testing of substances (water, paint, etc.) which are sent to a laboratory for analysis." The Medicaid definition attempts to ensure that the scope of an investigation is limited to services that are "medical" in nature.

The GAO found that only half of State Medicaid agencies now cover any investigations to determine the source of lead, that many States consider such investigations as an "optional" coverage service and that most State Medicaid agencies do not have formal agreements with other (public health) agencies for conducting such investigations or conducting more extensive environmental investigations that may be required but are not covered by Medicaid. Given these findings, HCFA will clarify that State Medicaid programs are required to cover limited investigations of the source of lead as described below and HCFA will work with CDC to assist State Medicaid agencies in developing formal agreements with other agencies to ensure that appropriate investigations to determine the source of lead are performed for Medicaid-eligible children.

The HCFA's manual issuance also indicates that, with respect to diagnosis, treatment and follow-up, providers should use their professional judgment in conjunction with CDC recommendations. While this section of the manual is not specific with respect to reimbursement for case management, the general requirements of EPSDT services are that any medically necessary services coverable by Medicaid must be provided to a child. Case management is a Medicaid-covered service. However, medical necessity is a State determination and some variation in services may occur from State to State or the responsibility for the case management of a lead poisoned child may be another agency's responsibility in some States. The HCFA is not aware of any States refusing to cover services for children with elevated blood lead levels. As part of our correspondence to State Medicaid agencies, however, we will clarify this requirement. The HCFA will pursue any reports of States refusing to provide services that are required under EPSDT.

In addition, HCFA does not generally delineate specific types of treatments to be provided to individuals. We believe that in the instance of a lead poisoned child, CDC's guidance and recommendations are the appropriate source of information. However, we



will clarify our policy to States on the requirement that all appropriate treatment coverable under Medicaid should be provided to children with elevated blood lead levels. While States are limited in the kind of lead investigations they can cover under the "regular" Medicaid program, there is an option for State Medicaid agencies that want to expand their coverage in this area. States can apply for a waiver under Section 1115 of the Medicaid statute to implement a demonstration program. Such a demonstration permits a State Medicaid program to implement innovative strategies for providing services to Medicaid eligibles, provided it meets certain requirements, such as budget neutrality. For example, HCFA recently approved an amendment to Rhode Island's Section 1115 Medicaid demonstration that will allow the State to receive matching funds for expenditures related to replacing windows in the homes of children diagnosed with lead poisoning. This innovative program will help to improve the health of children by removing the source of contamination from their homes. The HCFA will provide technical assistance to any State in developing such innovative demonstration projects.

#### **INTEGRATING LEAD SCREENING WITH OTHER PREVENTIVE HEALTH CARE FOR CHILDREN**

##### **GAO Recommendation #5**

To improve the efficiency and effectiveness of lead screening and other preventive health care efforts and marshal federal health care resources for reaching at risk children, the Secretary of HHS should identify ways to integrate lead poisoning prevention activities with other health programs and continue efforts to improve children's access to preventive health services. The Secretary should explore options for better coordinating interventions to improve lead screening and treatment with those to improve other preventive health services, such as immunizations. As part of these efforts, the Secretary should consider establishing a formal agreement or requirements for coordinating lead screening and treatment activities with those of the U.S. Department of Agriculture's WIC program.

##### **Department Comment**

The Department agrees that it is critical that improvements are made in the effectiveness and efficiency of lead screening efforts. The Department will work with all appropriate agencies to improve children's access to lead screening as part of preventive health services.

An example of coordination efforts already under way is CDC's Advisory Committee on Childhood Lead Poisoning Prevention. This group was recently re-chartered and now includes ex-officio representatives from HCFA and HRSA. A screening working group



and case management working group has been organized by the Advisory Committee and has begun addressing a number of issues raised in GAO's report, including improving managed care contracts and improving reimbursement for services.

### **Technical Comments**

1. The NHANES III is inconsistently named and referenced throughout the report. Sometimes it is the "HHS survey," other times it is the "CDC survey" or the "CDC NHANES survey."

2. It would be useful to define "elevated" blood lead in the Executive Summary.

3. Page 1, paragraph 1: It should be made clear that the estimate of children with elevated blood lead levels is based upon data collected during the period 1991-94.

4. Page 1, paragraph 3, sentence 2: Add the word "national" before "health surveys," so that the sentence reads "However, national health surveys conducted periodically..."

5. Page 2, last paragraph, first sentence: Change to read "Screening activities supported by federal subsidy programs often do not occur because federal screening policies have not been followed at the state level."

6. Page 3, Second (full) sentence: Delete the phrase, "Despite these views,...." and begin the same sentence, "And most State officials...." Add the following sentence: "Such data could be used to demonstrate the prevalence of exposure where it actually exists."

7. Page 3, paragraph 2, fourth line: Replace "...show the extent services...." to "...show the extent to which services...."

8. Page 4, paragraph 2, first sentence: Change to read "GAO also found...children with elevated blood lead levels who were in federal health care subsidy programs."

9. Page 4, paragraph 2, fourth sentence: Change to read "The statistical projections... children aged 1 through 5 with elevated blood lead levels who are targeted by federal health care subsidy programs, over 400,000...."

10. Page 11, paragraph 1, sentence 3: The estimate of 900,000 is used here. Although it is qualified with the word "nearly," the estimate that is cited everywhere else in the report is 890,000.

Now on page 2.

Now on page 2.

Now on page 4.

Now on page 4.

Now on page 4.

Now on page 5.

Now on pages 5-6.

Now on page 14.



Now on page 16.

11. Page 13, paragraph 2: Change the phrase "old toys" to "old and imported toys."

Now on page 17.

12. Page 14, paragraph 3: Change the first sentence to read, "CDC is the primary agency responsible for issuing recommendations for screening and treating young children for lead poisoning."

Now on page 17.

13. Page 14, Last sentence: Change "diagnostic" to "diagnosis."

Now on page 20.

14. Page 17, paragraph 3, sentence 1: Delete the word "phase" from this sentence. If desired, insert the years of the survey, 1991-94.

Now on page 20.

15. Page 17, footnote 11: Replace the entire footnote with the following, "the NHANES has been conducted periodically since 1960. This analysis is from Phase 2 (1991-94) of NHANES III; U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, National Health and Nutrition Examination III, 1988-94, NCHS CD-ROM, Series II, No. 1A, ASCII Version, July 1997."

Now on page 20.

16. Page 17, Footnote 11: Change "1994-1994" to "1991-1994."

Now on page 21.

17. Page 18: There is no references to Appendices III and IV, where as other methodologic appendices have been referenced.

Now on page 27.

18. Page 24: Insert "CARE SUBSIDY" between "HEALTH" and "PROGRAMS."

Now on page 27.

19. Page 25, line 3: Change "federally supported programs" to "federally supported health care subsidy programs."

Now on page 28.

20. Page 25, Table 3.1: Change "Medicaid children" to "Medicaid enrolled children," and "WIC children" to "WIC enrolled children."

Now on page 28.

21. Page 25, Table 3.1, first sentence: Change "people's recall" to "people's awareness and recall."

Now on page 33.

22. Page 30, first sentence: Change "federal health programs" to "federal health care subsidy programs."

Now on page 44.

23. Page 41, paragraph 2, sentence 4: Reword the sentence as follows: "We analyzed data for selected large counties."

Now on page 51.

24. Page 48, paragraph 3, first sentence: Delete "such as NHANES."



Appendix VIII  
Comments From HHS

Now on page 51.

25. Page 48, paragraph 3, sentence 2: Add at the beginning of the sentence, "As a case management tool, CDC requires its grantees...."

Now on page 51.

26. Page 48, paragraph 3: Change the last word of paragraph from "1998" to "1999."

Now on page 59.

27. Page 58, paragraphs 1 and 2 (on collaboration): It is important to note that in 1997, collaboration as an evaluation factor was more heavily weighted than in previous years.

Now on page 59.

28. Page 59, sentence 2: Change to read "The 1998 study, supported by CDC, of Medicaid managed care contracts...."

Now on page 62.

29. Page 62, paragraph 2, last sentence: The phrase should be changed to read "...opportunity for clarifying expectations about provider performance in managed care contracts...."

Now on page 63.

30. Page 63, paragraph 3 (indented): The phrase following item (1) should read "...in their states or communities, build systems to collect, manage, and analyze these data, or commit to conducting...."

Now on page 68.

31. Page 65, paragraph 2, sentence 1: Omit last portion of sentence: "...and is also representative within certain counties." Add new sentence to follow: "The primary sampling units in NHANES generally represent single large counties or a group of small contiguous counties."

Now on page 68.

32. Page 65, footnote 3: Add "years" after "...and persons 60...."

Now on page 68.

33. Page 66, first line: Delete, "...and invited to participate." and add "...based on demographic characteristics." after "...selected households were identified...."

Now on page 69.

34. Page 66, paragraph 3, sentence 3: This sentence is confusing and probably can be simplified. The point that GAO needs to make is that the information about income and insurance status was collected for the whole family, and was therefore not child-based.

Now on page 71.

35. Page 68: Are the two tables correctly labeled? Why is the sample size for all categories in both tables the same, except for "All children?"

Now on page 72.

36. Page 69, Note: It is not clear that this note about elevated BLLs is for all tables in Appendix I.



# GAO Contacts and Staff Acknowledgements

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## GAO Contacts

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## Staff Acknowledgments

In addition to the persons named above, the following persons made important contributions to this report: Matthew Byer conducted the Medicaid survey, Timothy Clouse analyzed the NHANES data, Evan Stoll, Jr., analyzed Medicaid billing data and health center samples, Patricia Yamane oversaw fieldwork at health centers and work related to treatment issues, Stanley Stenersen guided the message development and report writing, George Bogart served as attorney adviser, Susan Lawes assisted with the Medicaid survey methodology, and Molly Laster compiled information on state screening and reporting requirements. Marsha Lillie-Blanton provided technical assistance on this assignment.















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