

The Child Health Law and Policy Project of the National Health Law Program

Prepared by: Jane Perkins, October 29, 1999

This past week, some attention was paid to the problems faced by young children who are being poisoned by lead. The week was designated by Congress as Lead Poisoning Prevention Week, and October 26th was Lead Safe America Day. To mark the occasion, the Administration issued a number of pronouncements, including a Dear Medicaid Director letter, a report to Congress on lead screening of Medicaid-eligible children, and a statement by Tipper Gore. This paper provides a brief background to the lead poisoning problem and discusses these Administration actions.

Background

Childhood lead poisoning is the number one environmental hazard facing children in the United States.

"Lead is a useful metal and a versatile, subtle, and persistent poison."⁽¹⁾ Lead poisoning can cause weakness, irritability, weight loss, vomiting, personality changes, constipation, headache, abdominal pain, and a "lead line" on the gums and in the bones. Later manifestations include retarded development, convulsions, and coma associated with increased intra-cranial pressure. Death can occur. Early detection and treatment of lead is essential because the cognitive deficits associated with lead poisoning are only partially reversed by a subsequent decline in blood lead levels.⁽²⁾

Lead poisoning is most common in children under age six. In these children, the blood-brain barrier is still forming, so lead can more easily cross from the blood to the brain. Children are exposed to lead because they put their hands in their mouths and they breathe: Young children

are more likely than older children and adults to engage in "pica" (hand to mouth) behavior that will allow them to ingest lead from paint, soil, or dust. Dust particulates containing lead also can be inhaled. The most likely sources of lead poisoning are paint and leaded gasoline deposited in the soil, and include, to a lesser extent, fruit tree sprays, artist's paints, solder, brass alloys, home-glazed pottery, and fumes from burning batteries.

A laboratory test is required to determine lead poisoning. It cannot be detected through a visual assessment, a verbal risk assessment, or -- with certainty -- through "robust" tests that measure for a number of conditions. A robust test, the erythrocyte protoporphyrin (EP) test, has been used to test for iron deficiency and lead poisoning, but the test does not accurately measure lower levels of lead poisoning. A blood lead test is needed and can be performed either venously or through a finger prick (assuming sterile conditions). Lead levels are considered "elevated" if they measure greater than or equal to 10 µg/dL of whole blood. Elevated blood lead levels may be addressed through a range of treatments, including inpatient and outpatient hospital services, physician services, case management, and environmental investigation to determine the source of the poisoning. Of course, removal of the source of the lead is the optimal prevention.

According to the GAO, almost 9 million children under age six - 16 percent of low income children and 21 percent of African American children living in older housing - are lead poisoned. Currently, three-fourths of the nation's housing contains lead paint.

The effects of lead and those who are likely to be affected by lead are well-identified, yet the General Accounting Office reports that only 20 percent of Medicaid-eligible children are being screened for lead poisoning - even though Medicaid-eligible children represent about 60 percent of all children with lead poisoning. U.S. General Accounting Office, *Lead Poisoning: Federal Health Care Programs are not Effectively Reaching At-Risk Children* (Jan. 1999). In previous GAO surveys:

81 percent of Medicaid children surveyed had not been previously screened. U.S. General Accounting Office, *Medicaid: Elevated Blood Lead Levels in Children 2* (Feb. 1998). [TEXT], [PDF], [SUMMARY] only about 21 percent of children aged 1 and 2 who are EPSDT eligible had been screened for lead poisoning. U.S. General Accounting Office, *Children's Health: Elevated Blood Lead Levels in Medicaid and Hispanic Children* (May 1998). (3) In sum, lead poisoning persists among low income children. On the whole, the states have a dismal record of implementing federal Medicaid requirements for lead screening, and the federal government has not taken adequate steps to monitor and hold the states accountable. The announcements of the past week go some way toward addressing these shortcomings at the federal level.

The Dear Medicaid Director Letter

On October 22nd, the Health Care Financing Administration (HCFA), the agency in charge of federal enforcement of the Medicaid Act, issued a Dear State Medicaid Director Letter discussing the "critical" need for states to adhere to federal policies regarding lead screening and follow-up services for children. A complete copy of the letter is reprinted below.

The Medicaid Act requires blood lead testing and treatment to be part of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.(4) In the letter, HCFA out that it

... has interpreted this language to require that all children enrolled in Medicaid should receive a screening blood lead test at 12 - and 24-months of age because this is the age when all children are most at risk. Children over the age of 24 months, up to 72 months of age, for whom no record of a previous screening blood lead test exists, should also receive a screening blood lead test.

States are instructed to cover any follow-up services that are within the scope of the federal Medicaid statute, including diagnostic or treatment services that are medically necessary. According to HCFA, this includes case management services and "one time" investigation to determine the source of the lead for children diagnosed with elevated blood lead levels. The environmental investigation service, however, is limited by HCFA to include only a health professional's time and activities during on-site investigation of a child's home (or primary residence). Thus, the agency is taking the position that Medicaid is not available for testing the substances that are gathered at the site, such as soil, water, and dust.

The Letter also informs states of HCFA's strategy to assure adherence to the federal

requirements. A task force has been formed, consisting of HCFA, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and the Administration for Children and Families. The task force will work to:

ensure compliance with federal policies. Using data from the GAO, the task force will work in those states that were identified as failing to adhere to the federal policies. In general, the agency notes the problems identified by the GAO in managed care settings. States are asked to target managed care organizations and educate them about the federal requirements, in part, by including specific provisions in their Medicaid managed care contracts. HCFA also notes that it will be "happy to provide technical assistance to states in developing innovative 1115 proposals," such as a recently approved Rhode Island demonstration project that replaces windows in homes of children with lead poisoning.

develop state-specific data. HCFA says that data on lead has been difficult to collect, particularly in managed care settings that often do not submit encounter-type data to the state. The agency says it is working on several ways to improve data collection. HCFA has revised the Form 416, the annual EPSDT reporting form, to require states to report the total number of screening blood lead tests furnished to eligible children.⁽⁵⁾ (While this change is important, it collects only the number of children screened without also asking for the number of children who are identified through the screen as having elevated lead blood levels. This information would provide invaluable epidemiological information and would be useful in verifying that children are receiving the follow-up care they need.)

develop a process for waiving universal blood lead screening for Medicaid children. Notably, "until we [HCFA] have appropriate criteria or a process in place, we cannot allow a state to waive the universal lead screening requirement for Medicaid-eligible children."

develop a strategy for educating providers and the public about lead poisoning resources.

promote working relationships among federally-funded childhood lead poisoning programs. States will be encouraged to use case management to coordinate services for children with elevated blood lead levels and to reach inter-agency agreements with state and local housing, lead abatement, and environmental investigation authorities.

The Report to Congress

As part of the Labor-Health and Human Services Appropriations for 1999, Congress requested a report on lead from HCFA. The action was taken in response to the January 1999 GAO report. HCFA has just responded to Congress' request in its Report on Blood Lead Screening of Children Served by Medicaid (Oct. 1999). The agency describes the steps it has taken in response to the GAO report, including: issuing the Dear Medicaid Director Letter, discussed above; revising the annual EPSDT reporting Form 416 to include reporting on lead screening, and instituting the Task Force. A copy of the report can be obtained from NHeLP - LA.

The Statement by Tipper Gore

During an October 22nd appearance with Rhode Island Senator Jack Reid, Tipper Gore "unveiled new steps the administration is taking to eliminate lead hazards." Mrs. Gore announced that the Department of Housing and Urban Development will release \$56 million in grants to remove lead hazards from the homes of low income families. Mrs. Gore estimates the grant will assist almost 30,000 children in over 20 cities and states. The grants will be used to fund initial inspection and risk assessments to identify the presence of lead-based paint in homes, provide blood testing for children prior to beginning hazard control work, remove leaded paint from homes and yards, provide temporary housing for families whose homes are being treated, and launch community-based education programs.

Mrs. Gore also discussed Medicaid coverage of lead screening and treatment. She said states are required to provide blood lead tests annually to all children under the age of two enrolled in the Medicaid program and to provide follow-up case management and treatment services when medically necessary. Mrs. Gore specifically noted the release of the Dear Medicaid Director Letter described above.

Tipper Gore is the honorary chair of the Campaign for a Lead Safe America, the Administration's campaign formed in November 1997 between HUD and EPA to address childhood lead poisoning.

1. Herbert L. Needleman, "Childhood Lead Poisoning: The Promise and Abandonment of Primary Prevention," 88 Am. J. Public Health 1871 (Dec. 1998).

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

3. Copies of GAO reports are available from: www.gao.gov. For additional information on lead poisoning and updates on federal and state activities, see www.aeclp.org, the web site of the Alliance to End Childhood Lead Poisoning.

4. See 42 U.S.C. § 1396d(r)(5). For additional information about EPSDT, please consult the children's health section of our web site, www.healthlaw.org.

5. For more extensive discussion of the changes to the Form 416, see NHeLP Child Health Law and Policy Project, Medicaid Services for Children: Federal Revisions to Reporting Form Raise Many Questions (Oct. 18, 1999) (available at www.healthlaw.org).

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

Center for Medicaid and State Operations, 7500 Security Boulevard, Baltimore, MD 21244-1850

October 22, 1999

Dear State Medicaid Director:

The Department of Health and Human Services (HHS) is committed to ensuring that all of America's children are free of lead poisoning. The purpose of this letter is to present you with the findings of a General Accounting Office (GAO) lead screening report to clarify the legal requirements for lead screening for children in Medicaid, and to update you on the activities of an HHS task force created to control lead poisoning.

Lead poisoning remains a significant health concern for young children. As you know, the General Accounting Office (GAO) released a report in January 1999 entitled "Lead Poisoning: Federal Health Programs are Not Effectively Reaching At_Risk Children." This report highlighted the low number of Medicaid eligible children who have been screened for lead poisoning as well as the number of states that are not adhering to Federal Medicaid lead screening policy. It is critical that State Medicaid programs adhere to the Federal Medicaid policies for lead screening and provide the medically necessary follow-up services as part of Early and periodic Screening, Diagnostic and Treatment (EPSDT) services.

GAO Report Finding

Research indicates that although Medicaid-eligible children represent approximately 60 percent of all children in the country with lead poisoning. That is why state Medicaid programs are required by Federal law and policy to cover screening blood lead tests for all children. And yet, the GAO report found that only 20 percent of Medicaid-eligible children had received any

screening blood tests. The report also identified problems with regard to state Medicaid coverage of case management services and the one-time investigation to determine the source of lead in children who are lead poisoned. Additionally, the report raised issues concerning the reliability of state Medicaid data on blood lead screening and the effect of Medicaid managed care programs on lead testing and data.

For your information, we have enclosed a copy of the Executive Summary and the Department's responses to GAO's recommendations (Enclosure 1) [not included on this website]. The full report may be downloaded from the GAO website at www.gao.gov.

Lead Screening Requirements in Medicaid

Even as the average blood lead level of children in this country continues to decline, lead poisoning among Medicaid-eligible and other vulnerable children remains a concern. As part of the definition of EPSDT services, the Medicaid statute requires coverage for children to include screening blood lead tests appropriate for age and risk factors. The Health Care Financing Administration (HCFA) has interpreted this language to require that all children enrolled in Medicaid should receive a screening blood lead test at 12- and 24-months of age because this is the age when all children are most at risk. Children over the age of 24 months, up to 72 months of age, for whom no record of a previous screening blood lead test exists, should also receive a screening blood lead test. In addition, states should cover any follow-up services within the scope of the Federal Medicaid statute, including diagnostic or treatment services determined to be medically necessary. Such services would include both case management services and the one-time investigation to determine the source of lead for children diagnosed with elevated blood lead levels

Part 5 of the State Medicaid Manual states that "investigations to determine the source of lead may be reimbursable... under certain circumstances." We are taking this opportunity to clarify this information. The term "may" does not mean this is an optional service. The intent was that certain medical circumstances must be present before the investigation is reimbursable as a Medicaid service, i.e., the child must have an elevated blood lead level. In addition, the scope of the investigation is limited. HCFA only reimburses for a health professional's time and activities during an on-site investigation of a child's home (or primary residence). Medicaid funds are not available for testing of environmental substances such as water, paint or soil. We will revise the State Medicaid Manual in the near future to make this requirement more explicit. In the meantime, we are bringing it to your attention now so that any misunderstanding is corrected.

Lead Screening Taskforce Update

HCFA has undertaken a comprehensive Departmental initiative to increase lead screening of Medicaid and other vulnerable children. We would also like to improve access to, and the provision of, needed follow-up services for children who are found to be lead poisoned. In addition to HCFA, the initiative includes the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the Administration for Children and Families (ACF) with assistance from the Environmental Protection Agency and the Department of Housing and Urban Development.

This group has developed a detailed strategy and timeline to implement five activities that are central to the GAO's findings:

- ensure compliance with Federal policies;
- develop state-specific data;
- develop a process for waiving universal blood lead screening for Medicaid children;
- develop a strategy for educating providers and the public about lead poisoning so that resources are focused on children who are the most likely to need help; and
- promote working relationships with federally-funded programs involved in childhood lead poisoning issues and other activities.

We also enclose information about HCFA's strategy for assuring that states are adhering to Federal Medicaid policies on lead screening and the provision of medically necessary follow-up services as well as describing the Departmental initiative in more detail. Finally, we discuss methods for sharing best practices. (See Enclosure 2)

We have discussed some of these issues and our activities with the National Association of State Medicaid Directors' (NASMD) Executive Committee at their meeting in March. This will also be an agenda topic at NASMD's Fall meeting- Please feel free to contact Cindy Ruff at 410- 786-3916 (e-mail: cruff@hcfa.gov) for further information.

Thank you for your attention to this very important matter.

Sincerely,

Timothy M WestmorelandDirector

cc:

All UCFA Regional Administrators

All I-ICFA Associate Regional Administrators for Medicaid and State Operations

Lee PartridgeAmerican Public Human Services Association

Joy Wilson National Conference of State Legislatures

Matt Salo National Governors' Association

Brent EwigNational Association for State and Territorial Health Officials

Enclosure 2

TASK FORCE UPDATE ON LEAD POISONING PREVENTION

Ensure Compliance with Federal Medicaid Policy

Using data from the most recent National Health and Nutrition Examination Surveys (NHANES) conducted from 1991 to 1994 and confirmed by (1994/995) data from 15 state Medicaid agencies, the GAO report indicates that only 20 percent of Medicaid-eligible children are being screened for lead poisoning. In addition, a national survey of state Medicaid agencies by GAO indicated that many states have not adopted the mandatory EPSDT lead screening policy. As indicated in the cover letter, States are to provide all Medicaid-eligible children with a screening blood lead test at 12- and 24-months of age. Children over the age of 24 months up to 72 months of age for whom no record of a previous screening blood lead test exists, should also receive a screening blood lead test. In addition, any follow-up services, including diagnostic or treatment services determined to be medically necessary that are within the scope of the Federal Medicaid statute, should also be provided. This would include both case management services and the one time investigation to determine the source of lead for children diagnosed with elevated blood levels

We intend to review the results of GAO's national survey and follow-up with those states which, based on the survey answers, appear not to be adhering to our policies on lead screening, coverage of case management services and coverage of investigations to determine the source of lead. We, along with our Regional Offices, are eager to work with States to ensure compliance with the law and program regulations.

According to GAO, approximately 42 percent of Medicaid-eligible children received their medical services through managed care arrangements. These health delivery systems are ideal for the provision of coordinated preventive services including lead screening. However, GAO found mixed results with respect to the effectiveness of managed care and lead screening and concluded that improvements are needed. Managed care plans and providers need to be made aware of the Federal lead screening requirements. We encourage all states that contract with managed care organizations to provide EPSDT services to Medicaid-eligible children to consider including specific language on lead screening requirements in your contracts. George Washington University's Center for Health Policy Research, under a contract with CDC, has developed optional contract specifications, including model language for lead screening. If you would like more information on this, you may contact the George Washington University website at www.gwumc.edu/chpr. While Medicaid covers the medical services that a child with lead poisoning needs, there remain other (non-medical) type services, such as housing, lead abatement and environmental investigation of the source of lead, that may also be needed in these cases. Case management services, which are claimed as a medical service, can be used to reach beyond the bounds of the Medicaid program to coordinate access to a broad range of services, regardless of whether the Medicaid program is finding the service to which access is gained. We encourage you to work with state and local agencies to develop interagency agreements to ensure that Medicaid children receive all the necessary services not covered under the Medicaid program. We (HCFA) will be working with our HRSA and CDC counterparts,

as part of the Departmental initiative, to assist you in this effort and to develop model interagency agreements that you can use.

Recently, Rhode Island was approved to expand its statewide 1115 Medicaid demonstration waiver to cover the cost of replacing windows in the homes of children diagnosed with lead poisoning. While replacing windows is not a covered item under the "regular" Medicaid program, Rhode Island was able to obtain HCFA approval for this because it financed the program with Medicaid savings created through other aspects of its 1115 waiver. This innovative program is expected to improve the health of lead poisoned children by removing the major source of contamination from their homes. We will be happy to provide any technical assistance that states need in developing similar innovative 1115 proposals for services for Medicaid children who are lead poisoned.

Develop State-Specific Data

Data on lead screening of Medicaid children is very difficult to capture on a national level for many reasons. In many states, public health departments provide lead screening to Medicaid-eligible children but do not bill the Medicaid agencies for these tests. State Medicaid agencies have no way of knowing these tests have been provided if no bill is received. For those Medicaid children served by managed care plans, encounter-type data and information is often not submitted to the state Medicaid agency. The laboratories (both public and private) that actually perform blood lead tests have a wealth of data, including prevalence data. However, while CDC grantees obtain data from public and private laboratories, it is not always statewide data, eligibility information is not always included in the submission, and this information is not usually shared with the Medicaid agency. As you can see, much work is needed in this area.

We are currently working on several ways to improve data collection for lead screening. We are revising the form HCFA-416, the annual EPSDT reporting form, to include a line requiring states to report the number of screening blood lead tests provided to children under the age of 6. The HCFA-416 collects data on EPSDT services for children receiving services in both fee-for-service and managed care arrangements. States should begin reporting this new data on April 1, 2000, which will be data for fiscal year 1999. The revision to the form is consistent with recommendations of GAO and has the support of the Administrator of HCFA and several members of Congress.

At the present time, HCFA is able to collect some data on lead testing from the Medicaid

Statistical Information System (MSIS) report. As of January 1, 1999, all states are required to submit this report. Nevertheless, we expect that it will take several years before MSIS will contain complete and reliable data for Medicaid-eligibles in both the fee-for-service and managed care systems.

We also intend to work with CDC and HRSA to address the data collection/sharing issues and problems. As you know, in a letter dated October 22, 1998, HCFA joined CDC and HRSA to launch a coordinated strategy aimed at reducing barriers to sharing data between Medicaid and health agencies. This strategy also supports innovative approaches to the design and implementation of state information systems that foster collaboration among these programs. We believe that lead screening data provides an excellent opportunity for different state agencies to work together towards a common goal. We encourage you to use the model data sharing agreement included in the October letter as a framework for developing an agreement to share and link lead screening data with relevant state level agencies. Regulations at 42 CFR 431.402(c) specify the reasons and purposes that are allowable administrative costs in the Medicaid program. 42 CFR 431.402(c) specifies that one such allowable administrative cost is administrative activities related to "providing services for recipients." We believe that sharing data, such as providing a list of Medicaid-eligible children or of Medicaid-eligible children who have received a blood lead test, with other state and local agencies involved in lead screening or lead poisoning prevention, would qualify as an allowable administrative cost. This linkage would allow the State Medicaid agency and other collaborating agencies to develop a data base to identify children who have not received screening blood lead tests and those at high-risk for lead poisoning. This type of data sharing or linking would fit the purpose of enabling more Medicaid children, particularly those at highest risk, to receive necessary services related to lead poisoning and would provide states with a match of 50 percent Federal financial participation.

Finally, we would like to ask you for any information you have on successful lead screening programs or interagency agreements which are working well in your states to ensure that children are receiving lead screens. We would like to collect "best practices" information to share with other states which may be having difficulty in determining the best way to screen children and collect and share appropriate data. Please send this information to HCFA, Center for Medicaid and State Operations, Family and Children's Health Programs Group, Attention: Cindy Ruff, 7500 Security Boulevard, S2-01-16, Baltimore, Maryland 21244.

Develop a Process for Waiving Universal Blood Lead Screening for Medicaid Children

When we revised our lead screening policy in 1998 to reflect the new CDC recommendations,

we recognized that it may be necessary to revisit our mandatory screening requirements as states developed their statewide lead screening plans. In a letter to you dated April 13, 1998, we encouraged your participation on the public health advisory committee in your state developing the statewide lead screening plan. We believe that Medicaid representation on this committee is of great importance to ensure that the concerns of the Medicaid population are addressed. According to the COC, children receiving public assistance remain at high risk for lead poisoning, despite the general overall drop in lead poisoning rates nationwide.

The GAO recommended that we develop a methodology for waiving Medicaid's universal screening requirement. We intend to work with CDC, its Advisory Committee on Childhood Lead Poisoning Prevention, and HRSA to develop a protocol and criteria to determine whether states have sufficient data and the information necessary to waive the universal screening requirement for all Medicaid-eligible children. We acknowledge that some states may not have a lead exposure problem or that it may be limited to only certain areas of a state. In these instances, mandatory lead screening of all Medicaid children may be unnecessary. However, until we have appropriate criteria or a process in place, we cannot allow a state to waive the universal lead screening requirement for Medicaid-eligible children. That is why we believe your participation in the development of these statewide lead screening plans is important.

Develop a Strategy for Educating Providers and the Public About Lead Poisoning

As part of the Departmental initiative, HCFA intends to work with other Federal agencies to better educate providers and the public about the continuing risk of lead poisoning especially for low-income children and those living in older homes. HRSA is already involved in educational activities such as the National Childhood Lead Poisoning Training and Resource Center and developing a national televideo conference for parents, caregivers and advocacy groups as part of its series of productions for Maternal and Child Health (MCH) Bureau grantees. CDC is funding the development of materials to educate the public and private providers, managed care organizations and parents about the importance of lead screening as part of its cooperative agreement with the Center for Health Policy research at George Washington University.

Promote Working Relationships with Federally-funded Programs Involved in Childhood Lead Poisoning Issues and Other Activities

We will be working with our counterparts on the Departmental workgroup to enhance federally funded activities in lead poisoning prevention, screening, treatment and other areas. Many

Federal agencies currently play a role and provide funding for childhood lead poisoning prevention activities. Through the Departmental initiative, we expect to better coordinate and enhance the Federal role. Specifically, HCFA intends to make presentations to NASMD and the Medicaid/Maternal and Child Health Technical Advisory Group to keep them apprised of lead poisoning issues and the collaborative work we are doing with other agencies. HCFA, HRSA and CDC intend to participate on key workgroups and committees on the Federal, state and community level. HRSA intends to convene an expert panel to explore the impact of lead poisoning on the MCH population. CDC will review its grantee performance goals to assure that collaboration with WIC, Early Head Start and Community Health Centers is specified.