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Improving Childhood Blood Lead Level Screening, Reporting, and Surveillance in Allegheny County, Pennsylvania

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Summary

Lead poisoning is a serious, preventable environmental health threat to young children in many communities throughout the United States (AAP, Committee on Environmental Health, 1998). One of the key goals for U.S. public health policy included in the U.S. Department of Health and Human Services (HHS) *Healthy People 2010* report is the elimination of elevated blood lead levels in children (see HHS, 2000). Achievement of this goal will require improvements in three general areas: (1) lead poisoning prevention; (2) screening, reporting, and surveillance of childhood blood lead levels; and (3) treatment of childhood lead poisoning. The focus of this report is on screening, reporting, and surveillance, which are critical, not only to the overall goal of eliminating lead poisoning, but to its prevention and treatment as well.

Fortunately, past efforts focused primarily on lead poisoning prevention have led to a decline in the number of children nationwide with elevated blood lead levels. Between 1999 and 2002, 1.6 percent of children one to five years old, or 310,000, had blood lead levels at or above the current recommended cutoff of 10 micrograms of lead per deciliter of blood ($\mu\text{g}/\text{dL}$), compared to 88.2 percent between 1976 and 1980 (CDC, 2005). Despite this significant reduction in the number of children nationally between the ages of one and five years who have elevated blood lead levels and the lower levels of blood lead observed, a number of issues continue to complicate effective eradication of this important public health problem.

First, the general perception that the problem of childhood lead poisoning has been resolved must be corrected. To place the rate of high lead levels (i.e., 1.6 percent of children nationwide) in context, the national prevalence rates for autism, childhood depression, and attention deficit hyperactivity disorder—other childhood health problems currently considered to be of critical concern—are 0.91 percent, 5 percent, and 3 to 5 percent, respectively (American Academy of Child and Adolescent Psychiatry, 2004a, 2004c, 2004b). Unlike these other conditions, however, the causes of childhood lead poisoning are known, and the condition is 100-percent preventable.

Second, recent national blood lead level data continue to show a clear racial disparity. Although the largest decrease in elevated blood lead levels (from 11.2 percent in 1991–1994 to 3.1 percent in 1999–2002) has been among non-Hispanic black children aged one to five years, this group of young children remains at greater risk for

exposure to harmful lead levels than non-Hispanic white children (1.3 percent) and Mexican-American children (2.0 percent) in the same age range (CDC, 2005). The risk of elevated blood lead levels also remains higher for other subpopulations of young children, including children from low-income families and children who live in older homes (CDC, 1997).

Third, because most young children with elevated blood lead levels have no obvious symptoms at the time of exposure, the prevention, detection, assessment, and management of lead poisoning and associated risk factors rely entirely on the results of blood lead screening tests.

Fourth, the absence of obvious symptoms belies the negative impact that even low levels of blood lead (i.e., less than 10 µg/dL) can have on a young child's cognitive, intellectual, and neurodevelopmental outcomes, and the very serious implications that these outcomes have for broader issues of national concern, such as school readiness and educational achievement levels.

Fifth, although eliminating childhood lead poisoning remains a high priority on the national public health agenda, responsibility for ensuring that at-risk young children are screened for lead poisoning and that the results are reported to relevant authorities is often fragmented at the county level, hindering adequate prevention, surveillance, and treatment efforts. In Pennsylvania, for example, all blood lead screening results must be reported directly to the state's disease-surveillance system by health care providers or state-licensed laboratories. The Allegheny County Health Department (ACHD) is no longer the first recipient of this data. Its current responsibility is limited to case management for those children identified as having elevated blood lead levels based on data reported at the state level.

For all of these reasons, now more than ever, effective screening, reporting, and surveillance of childhood lead poisoning requires the concerted, proactive, and coordinated effort of state and local public health officials, health care and health plan providers, community agencies, and parents. Such efforts are particularly important in communities with high rates of reported elevated blood lead levels or with inadequate data on the prevalence of elevated blood lead levels, as well as in communities with older housing, which increases the risk of young children's exposure to harmful lead levels.

Pittsburgh ranks 28th on the Centers for Disease Control and Prevention (CDC) list of the 129 cities with the greatest number of children estimated to have elevated blood lead levels (PA DOH, 2005). The CDC and the American Academy of Pediatrics (AAP) recommend that communities with comparable blood lead levels institute universal, rather than targeted or selected, blood lead screening. Moreover, many children in Allegheny County belong to high-risk groups (i.e., they live in households that are below the poverty level or in census tracts where the median-year housing was built before 1950).

In light of the issues raised above, the RAND Corporation, in collaboration with the University of Pittsburgh Office of Child Development, was commissioned by Healthy Home Resources to do the following:

- Review the quality of existing data on blood lead screening, reporting, and surveillance for young children in Allegheny County, and, if feasible, to use this data for estimating (1) the prevalence of childhood lead poisoning in Allegheny County and (2) the number of young children in Allegheny County with blood lead levels of 10 µg/dL or greater who have not been screened.
- Identify key barriers to screening, reporting, and surveillance efforts in Allegheny County, and potential strategies for overcoming them.
- Develop a set of recommendations for improving screening, reporting, and surveillance in Allegheny County.

Existing Data on Childhood Blood Lead Screening, Reporting, and Surveillance in Allegheny County

Data on blood lead screening from three extant databases were examined: the National Health and Nutrition Examination Survey (NHANES), the Pennsylvania National Electronic Disease Surveillance System (PA-NEDSS), and the Pennsylvania Medicaid database. An analysis of each database with regard to data characteristics and data quality revealed the following:

- The NHANES sample selection process and overall study methodology ensure the reliability of its results for the nation as a whole. However, the ability to make predictions from this data regarding local prevalence rates is limited. At best, these data provide an *approximate* range of the number of children with elevated blood lead levels in Allegheny County.
- PA-NEDSS has significant potential for providing comprehensive, timely, and high-quality data. However, the lead component of PA-NEDSS currently has a number of limitations: a quality review process that has only recently been implemented, missing information, an inability to assess the completeness of reporting, and an inability to cross-reference the information with Medicaid data.
- Medicaid claims data indicate only that a lead screening was completed and a claim was submitted; they do not specify blood lead levels in children who were screened nor whether the blood lead levels were elevated. The Medicaid database does include the ages of all children enrolled in Medicaid and, if applicable, their physical health managed care organizations (MCOs) and primary care providers. Thus, the relevant MCO or Office of Medical Assistance Program (OMAP) can

determine which Medicaid children are missing a lead screening and follow up as needed to ensure that blood lead level screenings are conducted in compliance with Medicaid requirements.

Based on the available data, we compared Allegheny County's screening and prevalence rates for childhood lead poisoning with other regions that have comparable levels of risk for childhood lead poisoning. The range of all children screened for childhood lead poisoning varies from 15.3 percent in Erie County to 2 percent in both Lancaster and Chester Counties; Allegheny County ranks sixth, with 5.4 percent of young children screened. Allegheny County's screening rate for children enrolled in Medicaid is fifth among the 12 Pennsylvania counties. Prevalence rates of blood lead levels of 10 µg/dL or greater among children screened under the age of six years range from 5 percent in Chester County to 22 percent in Lancaster County. Allegheny County's prevalence rate of 5.9 percent ranks it fourth lowest among the 12 counties. In comparison, Rhode Island's screening rate is 87 percent, and the prevalence rate for lead poisoning in this state (which is approximately the same size as Allegheny County) has declined to below 4 percent in 2003 from more than 14 percent a decade ago.

Given the limitations of the data described above, it is impossible to know with certainty the extent of the childhood lead poisoning problem in Allegheny County. However, estimates based on the available data suggest that 987 children between the ages of one and five years and 1,771 children under the age of six years with Medicaid benefits who have not been screened are likely to have blood lead levels of 10 µg/dL or greater.

Screening for Childhood Lead Poisoning in Allegheny County

According to the 1998 Medicaid Manual, a lead screening test must be provided to all children 12 to 24 months old who are enrolled in Medicaid. A child between 36 and 72 months of age who has not received a prior blood lead screening test must be screened. No risk assessment is required. For all other children, the blood lead screening recommendations of the CDC or the Health Resources and Service Administration should be followed as appropriate and unless superseded by state or county recommendations. The Pennsylvania Department of Health (PA DOH) Lead Elimination Plan calls for universal screening of all children without a confirmed prior blood lead test at the ages of one and two years and of all children three to six years old (PA DOH, 2005). The ACHD endorses the PA DOH's call for universal screening of all children at the ages one and two years.

Although national surveys of pediatricians indicate that they know the Medicaid requirements and CDC recommendations for childhood lead screening, available data

at the national, state, and local levels suggest that these guidelines are often not followed. A number of barriers currently work against adequate childhood lead screening in Allegheny County.

First, the dramatic reduction in extremely high blood lead levels in young children has reinforced the general perception that childhood lead poisoning is no longer a public health concern and that screening is not important for young children. Second, federal screening requirements and state and local screening recommendations notwithstanding, many health care providers may be following a policy of targeted screening, which adds several decision points to the determination that a child is at risk for lead poisoning. At each of these decision points, some at-risk children may not be identified and therefore not screened. Third, there are reported concerns about drawing blood from young children, the appropriateness of capillary samples, and the skills of the staff collecting the samples. Fourth, because many health care providers prefer to conduct lead screening tests through venous blood draws and do not have a readily available pediatric blood-drawer, many children are referred to off-site laboratories for testing. This requires a number of additional steps by the parent or guardian, including identifying and finding the laboratory, arranging for transportation to get there, taking time off from work, and finding child care for any other children who must remain at home, to name a few.

Reporting and Surveillance of Childhood Lead Poisoning in Allegheny County

Reporting the results of childhood blood lead screens is essential for two reasons: It expedites the case management and/or treatment of an individual child with an elevated blood lead level, and it provides the data necessary to characterize the epidemiology of elevated blood lead levels (PA DOH, 2005). Complete and accurate surveillance information about local lead poisoning risk factors can help guide development of appropriate screening recommendations, reinforce public education efforts regarding the importance of childhood screening, and encourage strategic partnerships for improving primary prevention efforts as well as screening and reporting.

Like most states, Pennsylvania has laboratory-reporting requirements to ensure that blood lead results are reported. However, a range of issues currently impedes reporting and surveillance processes in Allegheny County.

First, representatives of some state-licensed blood lead laboratories that serve health care providers in Allegheny County express difficulties associated with reporting electronically to PA-NEDSS using the specified HL7 format.

Second, many of the professionals involved in surveillance systems and at local laboratories report that health care providers are “notorious” for providing incomplete patient and/or lead test information on specimens sent for external processing and

reporting. Some laboratories will follow up with providers to obtain the required information; others will report to PA-NEDSS only the information they are provided. In particular, the lack of Medicaid status information for blood lead specimen results entered into PA-NEDSS makes it impossible to reliably cross-reference PA-NEDSS data with Medicaid data. Since the Pennsylvania Department of Public Welfare (PA DPW) no longer collects blood lead levels for young children when they are screened, it can be difficult to identify children who require a follow-up evaluation.

Third, until recently, there have been very few staff within the PA DOH assigned to monitor blood lead level data and identify data integrity problems. The approach of the PA DOH has been to hold the laboratory responsible for complete information, but laboratory-licensing procedures do not include adequate review of adherence to reporting requirements for blood lead level screening.

Fourth, the local Medicaid MCOs interviewed indicate that historically the PA DPW OMAP has not aggressively monitored blood lead screening rates. Follow up for non-Medicaid children referred for blood lead screens who are not tested is more complicated, since there is no ready mechanism for others outside the provider's office to identify them.

Conclusions and Recommendations

The findings of this study suggest that current blood lead level reporting and surveillance data are inadequate for accurately assessing the true prevalence of childhood lead poisoning in Allegheny County or the number of children who are at risk for lead poisoning but have not yet been screened. Thus, there is a clear need for more diligent state and local involvement to ensure that at-risk children in Allegheny County are screened, and that the information is reported appropriately.

At the state level, we recommend the following long- and near-term actions by the public entities that have a mandate to address these issues. These entities include the PA DOH, PA DPW, the Pennsylvania Department of Insurance (PA DOI), the ACHD, and the Medicaid MCOs serving Allegheny County.

- Implement the PA DOH Lead Elimination Plan's recommendation to institute universal blood lead screening for *all* children at one and two years of age.
- The PA DPW Office of Child Development and the PA DOH should request that the PA DOI adopt the Medicaid blood lead screening requirements for children who are beneficiaries of the State Children's Health Insurance Program (SCHIP).
- The PA DOH and the PA DPW should use one integrated database (i.e., PA-NEDSS) for surveillance of childhood blood lead levels in Pennsylvania.

- The PA DOH should enforce the current requirements for blood lead reporting to PA-NEDSS, including standards of reporting that must be met by all state-licensed laboratories. At a minimum, the PA DOH should require that information on children's insurance include Medicaid identification.
- The PA DOH should also provide more extensive technical assistance and support to state-licensed blood lead laboratories on proper electronic reporting.
- The PA DPW should reinstitute the requirements for reporting blood lead levels for all Medicaid children who are screened, or explore other options for obtaining this information, such as utilizing PA-NEDSS data.
- The PA DPW OMAP should step up its efforts to aggressively monitor current Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program requirements for childhood blood lead level screening, establishing a goal of 90-percent compliance for MCOs in Allegheny County by 2006. Managed care contracts should be revised to include quality or performance standards relating specifically to lead.
- The PA DOH and the PA DPW should establish procedures for cross-referencing blood lead level surveillance data in the PA-NEDSS and Medicaid databases no later than July 2006.

At the county level, we recommend the following actions, to be implemented under the guidance of the ACHD.

- The ACHD, the Medicaid MCOs serving Allegheny County, and interested local organizations should enhance public education and awareness efforts targeted at parents and health care providers about the importance of repeat blood lead level screening at age two and the adverse effects of blood lead levels of 10 µg/dL or higher on early childhood neurodevelopment.
- Health care providers should also be educated on the validity of capillary draws. The PA DPW, the ACHD, and Medicaid MCOs should assume responsibility for ensuring that health care providers receive training and kits for in-house capillary specimen collection (including filter papers) and the export of specimens for all Medicaid-enrolled children to licensed blood lead laboratories. The ACHD and the PA DOH should strongly encourage the adoption of the same practices among private commercial insurers for all other children.
- The Pennsylvania Chapter of the AAP should add blood lead screening tests to the immunization records they provide to parents.
- ACHD should establish a two- to three-year pilot program with the Alliance for Infants and Toddlers (Alliance) for developmental screening and tracking of a sample of children with blood lead levels of 10 µg/dL or higher, thus offering these children the benefits of the developmental screening and tracking process already conducted by the Alliance.

- All Medicaid MCOs serving Allegheny County should send feedback reports to their network providers on individual Medicaid children not screened for lead poisoning, including comparative data on blood lead screening compliance rates across practices. For all other children, ACHD and SCHIP administrators should encourage health care providers to develop an internal tracking (“tickler”) system for identifying individual children for whom a blood draw was ordered by an external lab but whose blood was not tested.