

Chapter 1. Introduction

Development of the Case Management Recommendations

This report from the Advisory Committee on Childhood Lead Poisoning Prevention (ACCLPP) is intended to facilitate the management of children with elevated blood lead levels (EBLLs) by providing case managers with information and guidance. Some of the assessments and interventions recommended herein will be the primary responsibility not of case managers, but of other individuals or groups—primary care providers (PCPs), public health agencies, nutritionists, managed care organizations, and environmental inspectors—for whom this document should be considered as only a supplementary, not primary, source of information. Through this document, however, case managers can become familiar with the activities and responsibilities of others, and thus be better prepared to offer them guidance, assistance, and support.

Many studies published since the 1991 Centers for Disease Control and Prevention (CDC) report *Preventing Lead Poisoning in Young Children* (1) have provided updated or new information that can assist case managers of affected children and their families. In response, some states and localities have implemented a variety of changes in case management procedures. The plethora of new information and the marked variation in assessment and management policies among various jurisdictions were the main stimuli for the development of these guidelines.

This report is divided into five chapters other than this introduction: four that present assessment and intervention guidelines from environmental, medical, nutritional, and developmental viewpoints plus one that presents caregiver education guidelines. Experts in each subject area were asked to summarize recommended case management actions; to provide a detailed, referenced basis for their recommendations; and to suggest the most important areas for future research to support, modify, or eliminate poorly justified or empirically based recommendations.

Recommendations in each chapter are based on the results of evidence-based studies wherever possible. The most convincing basis for a specific recommendation is data from prospective, randomized, controlled trials. Unfortunately, such data are scarce; therefore, experts who developed each chapter had to rely primarily on softer data from cross-sectional studies, cohort or case controlled studies, uncontrolled studies, epidemiologic data, and—if appropriate—case reports or animal studies. They were also asked to note whether studies of interventions used to support their recommendations were efficacy studies (studies performed under ideal conditions) or effectiveness studies (studies performed in ordinary settings).

In the absence of sufficient study data, the opinions of respected authorities were considered in the formulation of these recommendations. Recommendations, particularly those not based on controlled studies, were often modified by the ACCLPP working group and subsequently by the full committee. Thus, in their final form, the recommendations in this report represent the consensus of the ACCLPP rather than individual opinions of the authors of each chapter.

This report is written primarily for those who will provide case management for children with EBLs and for health department personnel who oversee case management follow-up. Because there is unavoidable overlap among chapters, interested professionals may gain insight from chapters covering areas outside their own expertise. For example, a nutritionist or a PCP will find iron stores and anemia discussed in both the medical and the nutritional sections.

Although the primary cause of EBLs in children is exposure to deteriorated paint in housing built before 1950, other sources of lead are found in some states and localities. Consequently, users of these guidelines may need to modify them to meet the needs unique to specific communities. Further, because the prevalence of EBLs among children will vary markedly among and within states, the number of children managed will show corresponding variation.

Because there is no apparent threshold below which adverse effects of lead do not occur, “EBL” must be defined arbitrarily. This report uses the definition given in the 1997 CDC report *Screening Young Children for Lead Poisoning* (2), which defined child blood lead levels (BLLs) ≥ 10 Fg/dL as elevated. Although the BLL at which particular elements of case management will be initiated is variable, education and follow-up BLL monitoring should be available for any child who has a confirmed BLL ≥ 10 Fg/dL. More intense management, including home visiting and environmental investigation, should be available to any child with a BLL ≥ 20 Fg/dL, or persistent levels in the 15 to 19 Fg/dL range.

Another variable, the duration of management, will depend on the effects of lead on the child being treated. As noted in Chapter 5, “Developmental Assessment and Interventions,” the effect of lead on a child may not be demonstrable until the child is well into the elementary school years, meaning that some children will need continued tracking by PCPs or others long after their case management ends.

The interventions recommended in this report are for the secondary prevention of EBLs—which is to prevent further lead exposure and to reduce BLLs in children who have been identified as having EBLs—and involve a number of scientific, technical, and implementation issues. The ultimate goal, primary prevention—the removal of harmful lead exposure sources (especially older, deteriorated housing) and the elimination of lead from products with which children may come in direct or indirect contact—involves other, sometimes overlapping, issues. The importance of primary prevention should not be overlooked, since the behavioral and cognitive effects of EBLs in young children are apparently irreversible.

Overview of Comprehensive Case Management

What Is Case Management?

Case management of children with EBLs involves coordinating, providing, and overseeing the services required to reduce their BLLs below the level of concern (i.e., 10 Fg/dL). It is based

on the efforts of an organized team that includes the child's caregivers. A hallmark of effective case management is ongoing communication with the caregivers and other service providers, and a cooperative approach to solving any problems that may arise during efforts to decrease the child's BLL and eliminate lead hazards in the child's environment. Case management is not simply referring a child to other service providers, contacting caregivers by telephone, or other minimal activities.

The current model of case management has eight components: client identification and outreach; individual assessment and diagnosis; service planning and resource identification; the linking of clients to needed services; service implementation and coordination; the monitoring of service delivery; advocacy; and evaluation (3). Once an eligible child is identified, the case manager should do the following:

- Visit the child's residence (and other sites where the child spends significant amounts of time) a minimum of two times.
- Assess factors that may impact the child's BLL (including sources of lead, nutrition, access to services, family interaction, and caregiver understanding).
- Oversee the activities of the case management team.
- Develop a written plan for intervention.
- Coordinate the implementation of the plan.
- Evaluate compliance with the plan and the success of the plan.

An environmental inspector should also visit the child's residence, with the case manager if possible, to conduct a thorough investigation of the site and identify sources of environmental lead exposure. The case management team can then use the results of this investigation to develop a plan to protect the child and correct hazardous conditions. Although environmental services may be provided by the case manager, the environmental inspector, or other program staff, the case manager is responsible for ensuring that a child receives services in a timely fashion.

Funding

Nationally, an estimated 83% of children with BLLs ≥ 20 Fg/dL are eligible for Medicaid (4). Both the case management of eligible children and the environmental investigation of their surroundings are reimbursable according to federal Medicaid policy, with each state responsible for setting reimbursement rates for eligible services.

Despite this, funding for services remains a critical resource issue for most states. Fewer than half of all states provide Medicaid reimbursement for lead follow-up services, with the level of reimbursement varying widely. In addition, most state programs do not know how many children with BLLs ≥ 20 Fg/dL also receive Medicaid. As of 2000, only 10 state lead programs

were able to successfully identify Medicaid children by linking their Medicaid and lead screening data bases (5).

Who Provides Case Management?

Ninety percent of programs use professionals (nurses or social workers) to deliver case management services (6). The case manager is usually a member of the local health department staff, although nearly half of all states also use other providers to deliver case management services.

In most cases, a management team can best meet the needs of an individual child. The team may include the case manager, the child's caregiver, the child's PCP, an environmental inspector, a health educator, a nutritionist, and the local public health agency.

Time Frames for Initiating Case Management Services

A case manager should schedule an appointment with the child's caregiver as soon as possible after being assigned to the case. Where feasible, public health agencies providing case management services should give priority to children with the highest BLLs and those less than 2 years of age. If the caregiver does not have a telephone, the case manager should visit the child's home and leave information at the door if no one is there. For children with BLLs ≥ 45 Fg/dL, the case manager should contact the child's PCP immediately to determine whether the child is being chelated at home or in the hospital. If the child is hospitalized, the initial visit may take place at the hospital. However, it is critical that team members conduct a hazard assessment in the child's home as quickly as possible. (See Chapter 2, "Assessment and Remediation of Residential Lead Exposure," and Chapter 3, "Medical Assessment and Interventions.")

<u>Blood lead level (Fg/dL)</u>	<u>Time frame for initial home visit</u>
15-19 (persistent*)	within 2 weeks of referral
20-44	within 1 week of referral
45-70	within 48 hours of referral
≥ 70	within 24 hours of referral

*two venous BLL measurements at this level more than 3 months apart

The Case Management Plan

The case manager is responsible for developing and implementing a written management plan based on a needs assessment done at visits to the child's home and other sites where the child spends significant amounts of time. Although all cases require a

minimum of two home visits, additional visits are often necessary. The caregivers also should be involved in developing the plan to ensure that it is realistic and meets their perceived needs. Areas the plan should cover are detailed in Table 1.1 and in specific sections of this report.

Coordination of Care by the Case Manager

The case manager is responsible for coordinating care and ensuring that all team members, including the caregiver, stay in communication and work together. Such communication includes verbal consultations with and written summaries of progress for team members. Case managers need not directly provide all follow-up care, but they are responsible for seeing that needed care is provided, including medical follow-up. In most jurisdictions, the environmental inspector or program issues and enforces lead hazard remediation orders. The case manager must be sufficiently knowledgeable about environmental investigation and follow-up, however, to ensure that inspection and remediation take place in a timely fashion and that short-term efforts are made to decrease an affected child's exposure to lead hazards. Similarly, the case manager is responsible for ensuring that someone follows up on referrals for other problems identified during case management.

Case Closure

It often takes an extended period of time to complete all the elements in a case management plan. When the environmental lead hazards have been eliminated, the child's BLL has declined to below 15 Fg/dL for at least 6 months, and other objectives of the plan have been achieved, the case should be closed. However, the case manager should discuss with the PCP and caregiver provisions for appropriate long-term developmental follow-up. (See Chapter 5, "Developmental Assessment and Interventions".) Case closure criteria should also include provisions for administrative closeout if at least three documented attempts to locate or gain access to the child and caregiver have failed.

Public Health Agency Role

Although the recommended public health agency activities are not part of case management *per se*, they are necessary to achieve optimum results. With their focus on the core public health functions of assessment, policy development, and quality assurance, public health agencies play a broad role in coordinating care at the state and local level. They also are responsible for initiating and implementing laws and regulations that will help to eliminate childhood lead poisoning. Local jurisdictions must have the political will

to take enforcement actions, where needed, to protect the health of children. The identification of affected children and exposure sources will have little impact unless lead hazards are eliminated in a timely manner. Public health agencies should take the following steps to coordinate care in six areas:

- *Screening and surveillance:* Ensure that screening of at-risk children is conducted in accordance with the state or local plan. Develop and maintain communication and good working relationships with PCPs and public and private health delivery organizations (including Medicaid).
- *Laboratory testing and reporting:* Require that EBLL test results (and, ideally, all blood lead test results) be reported in a timely and accurate manner, and provide oversight to ensure such reporting. Implement quality control measures for both environmental and blood specimens to ensure the validity and reliability of results.
- *Case management:* Set standards for follow-up of children with BLLs ≥ 10 Fg/dL; ensure that these standards are met. Establish procedures for identifying new cases, assigning cases to case managers, providing oversight of case management activities and case managers, and providing oversight for environmental inspection and remediation. Secure Medicaid reimbursement for case management and environmental services. Identify service gaps and take appropriate action.
- *Care coordination:* Work with public and private organizations including health care providers, managed care organizations, Medicaid agencies, housing organizations, mortgage lenders, property owners, and community groups. Provide consultation, education, and technical assistance to these groups, and prepare and distribute educational materials to them. Develop program policy supporting the effective management of children with EBLs (7).
- *Environmental interventions:* Ensure that laws and regulations related to lead hazard remediation are sufficient to address identified hazards. Enforce safety standards for lead in housing, food, and water. Oversee appropriate exposure reduction for each child. (See Chapter 2, “Assessment and Remediation of Residential Lead Exposure.”)
- *Evaluation:* Evaluate and report on the outcomes of the follow-up care provided to children with EBLs. Promote necessary changes in programs and policies. Develop an annual report that includes evaluations of screening, reporting, and case management efforts.

General Considerations

There are several guiding principles to consider when making recommendations for children with EBLs. First, interventions should be directed at children whose risk for lead exposure is high. Second, where possible, interventions should be targeted at children less than 2 years old because neurotoxicity is greater and lead exposure is more likely to result in a rapid increase in BLLs in very young children. Finally, when intervention recommendations are based on tenuous data or on expert opinion, as are some in this document, case managers and other involved professionals should more than ever remember *primum non nocere* (first, do no harm). Most children with EBLs come from economically disadvantaged families who may have difficulty meeting the daily challenges of life and who may be overwhelmed if presented with a long list of interventions. Further, as has been found in many studies of interventions to combat other childhood problems (injury prevention, dietary counseling), behavioral change recommendations usually have only a modest effect at best. Thus, better results may be achieved by focusing on the most important recommendations (usually those designed to eliminate environmental lead hazards) and assisting caregivers in implementing them. Encouraging and supporting families without making them feel guilty for their child's EBL or making unrealistic demands on them may offer the greatest benefit to the child.

References

1. CDC. Preventing lead poisoning in young children. Atlanta, Georgia: US Department of Health and Human Services, CDC; 1991.
2. CDC. Screening young children for lead poisoning: guidance for state and local public health officials. Atlanta, Georgia: US Department of Health and Human Services, CDC; 1997.
3. Weil M, Karls JM. Case management in human service practice. San Francisco, CA: Jossey Bass Publishers; 1985.
4. US General Accounting Office (GAO). Medicaid: elevated blood lead levels in children. GAO/HEHS-98-78. Washington, DC: GAO; 1998.
5. National Center for Lead-Safe Housing. Another link in the chain update: state policies and practices for case management and environmental investigation for lead-poisoned children. Washington, DC: Alliance to End Childhood Lead Poisoning and the National Center for Healthy Housing; 2001.
6. Alliance To End Childhood Lead Poisoning, the National Center for Lead-Safe Housing. Another link in the chain: state policies and practices for case management and environmental investigation for lead-poisoned children. Washington, DC: Alliance to End Childhood Lead Poisoning and the National Center for Lead-Safe Housing; 1999: p. 33.
7. Epstein SG, Taylor AB, Brown MJ. Coordinating care from clinic to community. Boston, MA: New England SERVE, Rhode Island Department of Health; 1998.

Table 1.1. Possible Elements of a Case Management Plan Based on Individualized Child Assessment

Activities	Partnerships needed	Health department resources	Refer to:
Reduction/elimination of environmental hazards	CM, EI, caregiver, PCP	Environmental investigation service or referral list of investigators, laboratory services	Chapter 2, Chapter 3, Appendix 1
Assessment of all possible exposure sources	CM, caregiver, CHW, caregiver, lead educator, EI	Case-management services, educational materials, HEPA vacs, cleaning materials, temporary coverings	Chapter 2, Chapter 6
Temporary/short-term hazard reduction	CM, caregiver, SW, PO, community- and faith-based organizations	Case-management services, referrals, linkages with PO, funds for relocation assistance	Chapter 2
Short-term reduction of residential hazards	CM, caregiver, SW, PO, EI, utility company, community- and faith-based organizations	Case-management services, lead hazard control program	Chapter 2
Temporary relocation to lead-safe housing	CM, caregiver, SW, PO, EI, occupational health specialist	Case-management services, funds for relocation assistance, lead-safe housing registry	Chapter 2, Chapter 3, Appendix 1
Long-term hazard elimination	CM, CHW, caregiver, PCP, EI, occupational health specialist	Educational materials on non-paint exposure sources, laboratory services	Chapter 2, Chapter 3, Appendix 1
Remediation/lead hazard control	CM, caregiver, SW, PO, EI, based organizations	Educational materials on non-paint exposure sources, laboratory services	Chapter 2, Chapter 3, Appendix 1
Permanent relocation to lead-safe housing	CM, caregiver, SW, PO, EI, utility company, community- and faith-based organizations	Educational materials on non-paint exposure sources, laboratory services	Chapter 2, Chapter 3, Appendix 1
Identification and removal of non-residential exposures (e.g., remedies, leaded objects, take-home exposures from parent's occupation)	CM, CHW, caregiver, PCP, EI, occupational health specialist	Educational materials on non-paint exposure sources, laboratory services	Chapter 2, Chapter 3, Appendix 1

Activities	Partnerships needed	Health department resources	Refer to:
Improvement of nutrition			
Caregiver counseling	CM, nutritionist, PCP, CHW	Case-management services, referrals, linkages, and educational materials	Chapter 3, Chapter 4, Chapter 6
Referrals to WIC or other community food resources	CM, nutritionist, PCP, CHW	Case-management services, WIC program, referrals	
Caregiver lead education			
Counseling re: lead and lead-exposure risks, decreasing identified risks, cleaning practices, importance of follow-up blood lead tests	CM, CHW, caregiver, PCP, EI	Case-management services, educational materials, cleaning materials	Chapter 6
Medical follow-up care			
Child with EBLL Siblings or other at-risk children living in home	CM, PCP, caregiver	Case-management services, transportation services	Chapter 3
Follow-up of other identified problems			
Counseling/referral for: medical services, early intervention and developmental assessment, housing services, social services, Head Start, parent support	CM, PCP, caregiver, community- and faith-based organizations	Case-management services, referrals, linkages	Chapter 3, Chapter 4

Abbreviations:

CHW—Community health worker
 CM—Case manager
 EI—Environmental inspector
 HA—Housing authority
 HEPA—high-efficiency particulate air (filter)

PCP—Primary care provider (health professional)

PO—Property owner

SW—Social worker

WIC—Special Supplemental Nutrition Program for Women, Infants, and Children