



# Coordinating Care from Clinic to Community

Quality Standards for Serving Children  
and Families Affected by Environmental  
Lead Hazards



New England SERVE



St. Joseph  
Health Services  
of Rhode Island

MAKE HEALTH PART OF YOUR FAMILY

Rhode Island Department of Health

*based on:*

**Enhancing Quality  
Standards and Indicators of Quality Care  
for Children with Special Health Care Needs**

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**New England SERVE**  
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Environmental Lead Hazards



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MAKE HEART HEALTH PART OF YOUR FAMILY

Rhode Island Department of Health

## ACKNOWLEDGMENTS

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The Division of Family Health of the Rhode Island Department of Health has been a leader in promoting a comprehensive system of quality primary prevention and treatment services for childhood lead poisoning. In soliciting a set of standards to support the development of family-centered care for children and families affected by lead, this state health agency has taken an innovative step toward assuring the full participation of families on the lead treatment team in their communities. This work would not have been undertaken without Dr. Peter Simon, whose energy and leadership have accompanied the project since its inception, and who continues to demonstrate an extraordinary commitment to the health and safety of all of the children in Rhode Island.

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We could not have had an *Advisory Council on Family-Centered Care for Children and Families Affected by Lead* without families. Parents caring for children with lead poisoning joined physicians, other health care providers, advocates and representatives from state and community-based organizations to enter into a year long partnership. This document reflects the willingness of all participants to collaborate in defining “how the system *ought* to work” for children and families. The honesty and respect demonstrated by families in those conversations can be found throughout the language of *Coordinating Care from Clinic to Community*.

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# Coordinating Care from Clinic to Community

Quality Standards for Serving Children  
and Families Affected by  
Environmental Lead Hazards

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The following organizations have endorsed *Coordinating Care from Clinic to Community: Quality Standards for Serving Children and Families Affected by Environmental Lead Hazards* as an important set of standards for building quality systems of care for children affected by lead.

**Alliance to End Childhood Lead Poisoning** Washington, DC

**American Academy of Pediatrics, Rhode Island Chapter**

**Childhood Lead Action Project** Providence, RI

**City of Providence, Mayor's Office** Providence, RI

**Family Voices of Rhode Island** Pawtucket, RI

**Greater Elmwood Neighborhood Services, Inc.** Providence, RI

**Hasbro Children's Hospital** Providence, RI

**Health & Education Leadership for Providence (HELP)** Providence, RI

**HELP Healthy Kids, A Lead Safe Center** Providence, RI

**Kent County Visiting Nurse Association** Warwick, RI

**Lifespan** Providence, RI

**Manchester Human Services Department** Manchester, CT

**Manchester Lead Abatement Project (LAP)** Manchester, CT

**Memorial Hospital of Rhode Island, Pediatric Environmental Lead Program** Pawtucket, RI

**Neighborhood Health Plan of Rhode Island** Providence, RI

**Rhode Island Department of Health** Providence, RI

**Rhode Island Department of Human Services, Center for Child and Family Health** Providence, RI

**Rhode Island Hospital** Providence, RI

**Rhode Island KIDS COUNT** Providence, RI

**The National Center for Lead-Safe Housing** Columbia, MD

*Dedicated to the goal of building  
healthy, lead-free, safe communities  
and family-centered systems of care  
for all children and families.*



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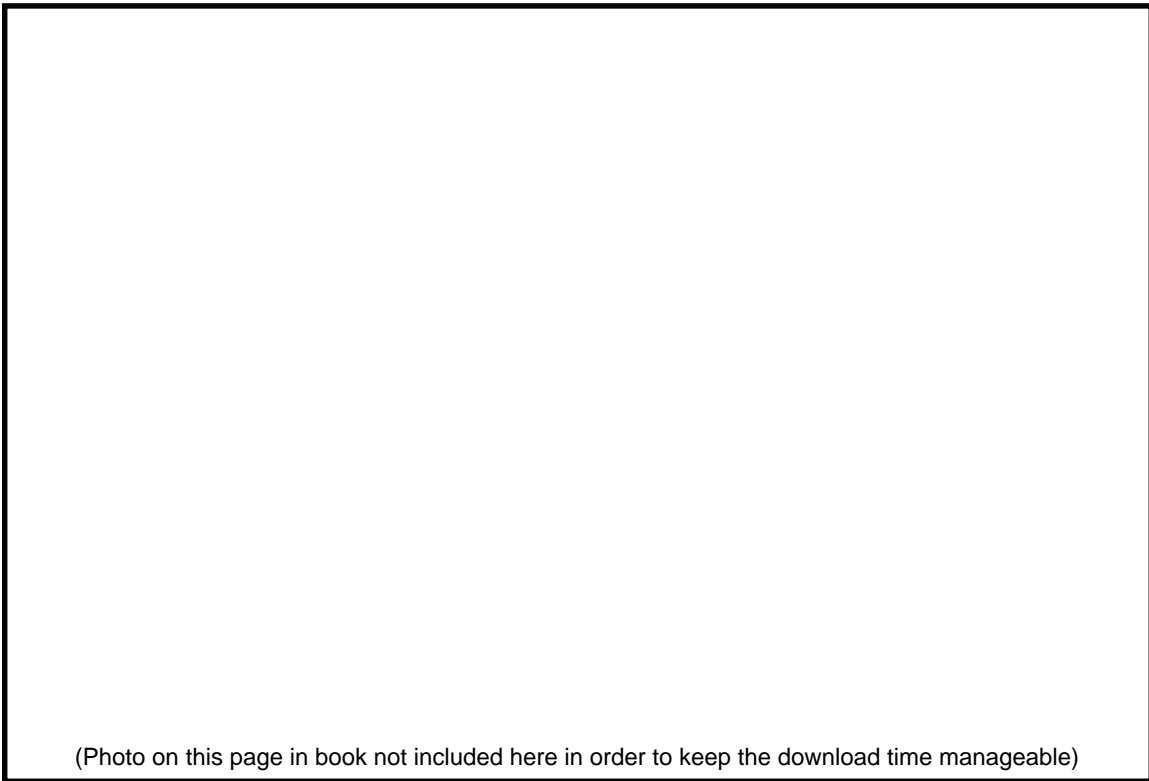
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# **INTRODUCTION**



This document, *Coordinating Care from Clinic to Community: Quality Standards for Serving Children and Families Affected by Environmental Lead Hazards* has been written to guide the development of family-centered systems of care for children affected by exposure to lead. The book identifies key elements that contribute to quality care for children who may have moderately to severely elevated blood levels, or lead poisoning. It also outlines community and state level responsibilities for prevention and care coordination.

Developing effective health services for children affected by lead exposure requires extensive coordination between multiple public and private agencies, clinical providers and community-based organizations. Many groups must cooperate in order to build a system that provides quality care. The health care system and patterns of service delivery are currently changing, with new roles emerging for parents, providers and communities. As concepts such as family-centered and community-based care are promoted nationally, specific indicators of these aspects of quality are needed in order to implement new directions in service delivery. *Coordinating Care* offers a set of ideal standards that can assist all partners on the lead treatment team to assess the quality of existing service systems and guide the development of family-centered care for this population of children and families.

The phrase *children affected by lead* describes a broad group of children, from those with mild lead exposure to those with lead poisoning. Children with *mildly elevated blood levels* (10-14 micrograms/deciliter or  $\mu\text{g}/\text{dL}$ ) although described as lead-exposed, are generally not considered candidates for individualized medical intervention. Children with *moderately elevated blood lead levels* include those with exposure to lead that is well above that found in the general population, 15-19  $\mu\text{g}/\text{dL}$ . Since lead exposure can affect children before there are any acute symptoms, the diagnosis of lead poisoning is almost always based on blood lead level. In this document, children with *severely elevated blood lead levels*, 20  $\mu\text{g}/\text{dL}$  or higher, are considered *lead poisoned*. Some of the interventions described in *Coordinating Care* are focused on children who receive specialized medical care by a lead treatment team. However, many of the education and prevention strategies described in this document, if applied widely within a community, will help protect children from the type of exposure which results in mildly elevated blood lead levels as well as more severe outcomes.

*Coordinating Care* is based on and largely adapted from an earlier publication entitled, *Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs*, that was developed and published by New England SERVE in 1989. Both of these documents reflect the values of family-centered, community-based and coordinated care. Beginning with the assumption that families of children affected by lead are both providers and consumers of health care services for their child, *Coordinating Care* offers strategies to ensure that family members are full partners on a team that responds to the needs of children exposed to lead. The standards also acknowledge that children affected by lead may require a continuum of services including primary care, specialized medical care, developmental assessments and a variety of family support services such as lead

abatement in housing, legal aid, transitional housing and community-based advocacy. Emphasizing the importance of coordination among all providers and reflecting the changing roles of families in the planning and delivery of care, *Coordinating Care* assumes that each family deserves the opportunity to choose a way of becoming involved that is comfortable for family members.

*Coordinating Care* acknowledges that both families and providers face barriers to obtaining and delivering quality care to children affected by lead. However, the burden of quality does not rest on these two groups alone. The development of improved service delivery systems demands effective advocacy and partnerships that extend beyond families and health care professionals to include educators, housing inspectors, lawyers, state and local departments of health, managed care organizations, state Medicaid agencies, elected officials at all governmental levels and concerned citizens in society at large. This document is dedicated to building those partnerships on behalf of children and families.

## **Background**

Despite the success of recent efforts to reduce lead in the environment, lead remains a pervasive environmental contaminant. An estimated 890,000 children in the United States have blood lead levels above 10 µg/dL, the threshold of concern established by the Centers for Disease Control and Prevention in 1991. Children, particularly African-American children living in the urban areas of the Northeast, are most likely to be affected. Poverty, with its implications for poor nutritional status and substandard or deteriorating housing, is one important determinant of risk to lead exposure. Low income children, as reported by the National Centers for Disease Control and Prevention, are more than four times as likely as children from middle class or high income families to have blood levels above 10 µg/dL.

A strong link has been established between low level lead exposure in early childhood and later decreased intellectual and academic performance. Even blood lead levels below those for which a child receives individualized health services or treatment can have later consequences; it is the duration, rather than the severity of the exposure that best predicts later effects. Children with chronic exposure are more likely to have lowered IQ, behavioral problems and, as a result, academic failure and increased risk for juvenile delinquency. Intellectual stimulation can limit the negative effects of extended environmental exposure to lead on educational attainment.

House dust contaminated by crumbling paint and ingested during normal hand to mouth activity is the most frequent source of lead for infants and young children. Once swallowed, lead is readily absorbed. Prevention strategies, therefore, are aimed at blocking the exposure pathway by reducing the level of contamination, limiting access to residential hazards and, through improved nutrition, decreasing the absorption of lead through the gastro-intestinal tract.

Because of the environmental aspect of the disease, effective interventions for lead poisoned children require extensive coordination. Many of those involved in primary prevention, as well as necessary follow-up activities, belong to professions which are not generally considered as part of the health care team. Coordination may need to involve property owners, mortgage lenders and lawyers. In addition, because of the interplay between poverty and substandard housing, in most regions of the country, governmental agencies that have responsibility for enforcement of federal, state or local housing or habitation statutes may also need to be involved.

The ultimate goal of preventing childhood lead poisoning as well as eliminating the further exposure to children who are already over-exposed can only be achieved through the reduction and control of residential lead hazards. However, the process of controlling or eliminating these hazards is often expensive, time-consuming and disruptive to families. Care coordination is particularly important during this difficult period.

As children with lead poisoning grow to school age, interventions are more likely to be directed at ensuring that the supports needed for successful educational development are available. Organization of services at the individual provider, program and agency level must assure that care is delivered in ways that respect the values and priorities of the individuals and families served and is responsive to changing developmental and educational needs.

Lead poisoning services and prevention efforts are further complicated by the recent shift in the focus of most public health agencies. In the past, these agencies have provided the vast majority of identification (screening) and follow-up services for lead poisoned children. As health departments move away from providing direct care and focus more of their resources on the core functions of needs assessment, quality assurance and policy development, screening and case management for lead poisoning are increasingly provided by a wide variety of private health care agencies and providers. In some areas, this shift from providing services in publicly funded clinics to providing services in private clinical settings has resulted in an increase in screening, and thus, identification of more children with lead poisoning. This change in the locus of delivery of health services has also resulted in health departments, as well as state Medicaid agencies, assuming the role of purchasers rather than providers of health care. Standards are needed to ensure that contracted health services for children with lead poisoning are effective, efficient and family-centered.

Building statewide and community-based capacity to meet the needs of children and families affected by lead presents significant challenges. Medical management of lead poisoning continues to evolve, while financial as well as organizational barriers may emerge that limit access to care. The need for community-wide prevention education is enormous. *Coordinating Care* offers a set of quality standards for serving children and families affected by lead as health care providers, policy-makers, advocates and families prepare to confront these challenges in the next decade.

## Uses of Coordinating Care

*Coordinating Care* has been developed for a broad range of users that includes families, physicians and other health professionals, hospitals, community health centers, state departments of public health, other public health agencies, as well as purchasers of health care services, such as managed care organizations, private insurers and state Medicaid agencies. Advocates for services for children affected by lead such as legal aid agencies, housing authorities, voluntary and community-based organizations may also use these standards to guide their efforts on behalf of children and families.

The 67 standards contained in *Coordinating Care* reflect best practices and can be used as an educational tool to define specific characteristics and components of quality care for children and families affected by lead. The document identifies key elements that contribute to quality family-centered care and support the coordination that is necessary across multiple public and private agencies, organizations and individual providers of clinical care. *Coordinating Care* may be used by health professionals to assess the quality of care being delivered in a particular setting or to develop new linkages within the community. It can also be used in clinical settings for training purposes to define family-centered care. The document describes the roles and responsibilities of those involved in providing care to children with elevated blood lead levels and will improve the ability of all providers to understand their shared responsibilities in building effective systems of care.

However, *Coordinating Care* goes beyond offering a set of standards for those caring for children who are already over-exposed to environmental lead sources. The document is also designed to guide partners within and outside the health care system in developing and implementing strategies to prevent lead exposure. The standards are designed to support advocacy efforts at all levels and to promote effective collaboration between families, health, social service, environmental and housing professionals.

Recognizing the need for a set of comprehensive standards of care for this population of children and families, the Division of Family Health within the Rhode Island Department of Health initiated a collaborative project. Working with St. Joseph Health Services of Rhode Island, an important provider of health services to children and families affected by lead in Providence, Rhode Island, and New England SERVE, a health policy research and planning organization that supports the development of quality services for children with special health care needs, this project was launched in May 1997. This document is a product of the hard work and commitment of an interdisciplinary Advisory Council that included families of children affected by lead, as well as representatives from a broad range of state and local agencies, health care providers, insurers, advocates and community-based legal aid and housing agencies. A list of the members of this group who gave generously of their time and expertise is provided at the front of this document.

## **Framework and Organization of Coordinating Care**

The ultimate goal of all health services for children is to ensure that the child grows and develops to optimal levels. However, quality of care cannot be measured solely on individual health status outcomes. Such an assessment, even if possible, would fail to recognize the many areas of influence within and outside the health care system that contribute to quality. Families who provide essential care-giving to children with ongoing health conditions need information and care coordination skills to help maximize their child's individual health. Activities of health care providers, whether as individuals or through a team, are often considered the first and most visible determinant of quality care. However, many health care providers function within an agency whose mission, organization and policies may or may not facilitate or support their efforts on behalf of children and families. Although less visible, such agency functions are critical to the delivery of quality care. Care for this population must also address the interaction of environmental factors such as housing and public policy with the delivery of individual health services. Providers and agencies practice within the larger social context of community, state and nation. Attitudes towards health, allocation of resources, and public policy development all contribute to how such services are delivered. While this conceptual framework applies to the design and delivery of general health care services, it is perhaps even more critical in an analysis of the complicated array of services needed by high risk, high cost populations such as children and families affected by lead.

The standards presented in *Coordinating Care* have been organized into five sections that parallel the model of the health care system described above:

- I. Individualized Services
- II. Health Care Professional and Team Characteristics
- III. Health Care Agency or Facility Responsibilities
- IV. Health Department Responsibilities
- V. Guidelines for Prevention and Community Supports

The first section focuses on the services received by individual children with moderately to severely elevated blood lead levels seen in clinics which specialize in providing care to lead poisoned children and their families. Section II defines the activities and responsibilities of health care and other professionals in delivering these services. Section III expands to include agency responsibilities for supporting and organizing services for children with moderately to severely elevated blood lead levels and their families, as well as educating families in ways to control or eliminate lead hazards before children are exposed. Section IV addresses the state and local health departments' roles in designing, implementing and coordinating community-based prevention activities, promoting technical assistance and consultation, and assuring high quality intervention services for over-exposed children. Section V reaches beyond the interaction of child, provider, agency and government and challenges communities to develop quality lead poisoning prevention strategies which are responsive to the needs of families with young children.

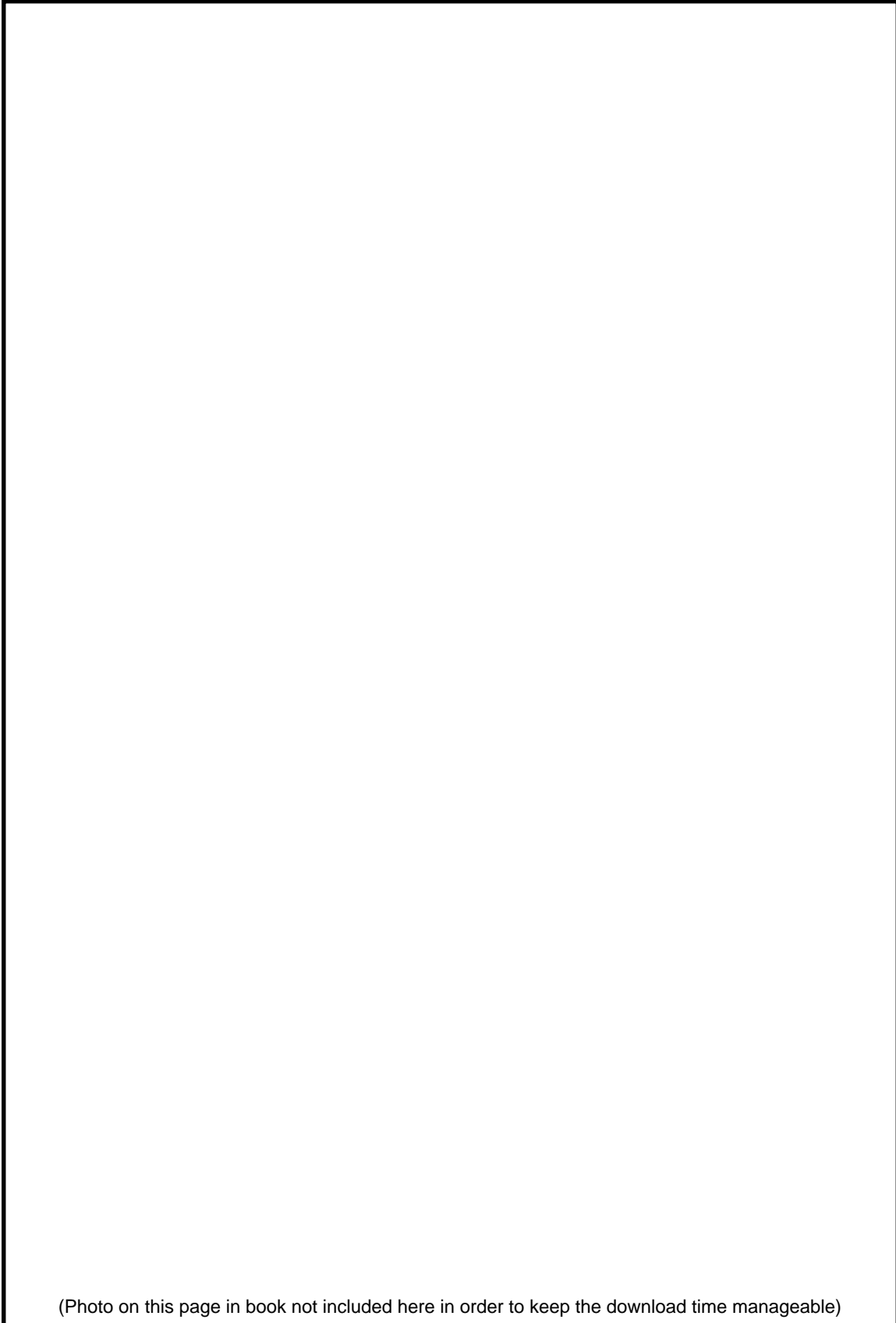
Like its parent publication, *Enhancing Quality, Coordinating Care* is a living document, providing a yardstick for quality as defined today. It offers a compilation of best practices that can guide the design and development of family-centered systems of care. As expectations for care have grown in the past, they shall continue to grow and change in the future. Definitions of quality and standards for care must reflect such changes and remain responsive to the special health care needs of children and families affected by lead.

This document also includes a glossary of terms related to lead poisoning and its prevention, a summary of Title X (P.L. 102-550), the Residential Lead-Based Paint Hazard Reduction act of 1993, and a listing of national organizations involved in advocacy and prevention of lead exposure in young children.

## **SECTION I.**

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# **INDIVIDUALIZED SERVICES**



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The standards in Section I are based upon the view of the child as an individual with unique physical, developmental, emotional, social, educational and cultural needs and the right to a safe environment. The standards recognize that the child is a member of a family whose partnership and collaboration with health care professionals are essential to the delivery of quality care and to the prevention of continued exposure to lead. To be effective, the process of planning and delivering care must reflect both the individuality of the child and the important role of the family.

Throughout this document, *family* refers to persons who consistently serve in care-giving roles for the child. These roles may be filled by a parent, foster parent, guardian, brother or sister. Other members of the extended family such as an aunt, grandparent or close friend may represent or substitute for the family at their request. In some cases, family members may require support services to fill these roles.

Another assumption underlying the standards for individualized services is that increased participation of children and families will result in more effective care. Lead poisoning is an environmental disease and, in the United States, most often caused when old peeling paint contaminates house dust or soil. Participation of the family is crucial to controlling a child's continued exposure to this toxicant. Many of the nutritional interventions and the developmental support which can prevent or limit the effects of lead exposure are most effective when the family understands their importance and is involved in their design. The developmental and behavioral consequences of lead poisoning may persist well beyond childhood. Families who participate in designing and delivering their child's care will become more effective advocates in the future.

The standards in Section I recognize and encourage the roles that families can play beyond those involved in providing care to an individual child. Families can share important information with health professionals about the effectiveness of educational materials, the success of referrals to outside agencies and their overall satisfaction with care. These insights are valuable aids to strategic planning and quality improvement efforts. Finally, as members of the larger community, families have much to offer in the area of prevention. Families should have the opportunity to participate in interagency program planning and policy-making. These broader roles for families are also addressed in Sections II, III, IV and V.

The standards in Section I are grouped into three major areas that reflect the basic values of family-centered, coordinated and accessible care:

- Child and Family Participation
- Planning and Coordination of Care
- Accessibility of Care

## **CHILD AND FAMILY PARTICIPATION**

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### **1.0 Families of children affected by lead and other primary caregivers are full members of the lead treatment team.**

- 1.1 Families participate in **decision-making** about all lead treatment services and in the development of the lead treatment plan for their child.
- 1.2 Families provide information about the **child's strengths, needs and culture** to other members of the lead treatment team.
- 1.3 Families provide **information** about **specific sources of lead** in their child's environment both at home and at other sites.
- 1.4 Families provide **feedback** to other members of the lead treatment team about the lead services their child receives.
- 1.5 **Trained interpreters** are available if needed, with attention to continuity of such services.

### **2.0 Families give informed consent for all lead treatment services received by their child.**

- 2.1 Families receive a clear explanation and full information about the **benefits and risks** of new treatments or research procedures, as well as alternative treatments, from the health care professionals on the lead treatment team.
- 2.2 Families can take the time they need to make **informed choices** about treatment decisions.
- 2.3 Families are informed of their **rights and responsibilities** under the health care and housing laws and regulations in their state.
- 2.4 Families are informed if there are **disagreements** among health care professionals about lead treatment services for their child, and understand their right to seek **other opinions** from professionals or other families caring for children affected by lead.
- 2.5 There is a process for **resolving conflicts** among members of the lead treatment team when there are different opinions about the plan of care.

### **3.0 Families have access to their child’s medical record, including lead treatment information.**

- 3.1 Families receive both **written and verbal information** about record-keeping policies, procedures and their rights to see and read their child’s medical records and lead treatment information.
- 3.2 Written information about record keeping policies is available in the **primary language** of families served.
- 3.3 Families are informed of any **statutory requirements** for information sharing.
- 3.4 **Copies of information** from the lead treatment record **and explanations** about the contents are provided without cost to the family upon request.
- 3.5 **Translation services** are available to explain the contents of the lead treatment record.
- 3.6 Families have the opportunity to add **written comments in a “family section”** of the lead treatment record.
- 3.7 Families use the **“family section”** of the lead treatment record to provide information about their child’s care or respond to other issues of concern to them.
- 3.8 Families **give written permission** when information from the lead treatment record is shared.

### **4.0 Families receive assistance in developing a summary of their child’s lead treatment.**

- 4.1 Families are encouraged and helped to set up a **family record-keeping system** to use information from the lead treatment record at home and with other community providers.
- 4.2 Families receive a **summary record** that includes current problems, diagnoses, treatments and guidelines for managing specific health crises.
- 4.3 Families receive assistance in **translating** the summary record into their primary language, if needed.

## **PLANNING AND COORDINATION OF CARE**

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### **5.0 A comprehensive assessment precedes and guides the development of a lead treatment plan for each child and family.**

- 5.1 Families develop a complete **list of persons and places** where their child is cared for, including day care and babysitting settings.
- 5.2 Families complete a **symptom and developmental checklist** that describes their child.
- 5.3 The lead treatment team works with families to identify and screen **brothers and sisters** or other at risk children in the family. Arrangements are also made to **screen pregnant** women and other adults when renovation, occupational exposure or cultural factors indicate increased risk.
- 5.4 The assessment is comprehensive and includes **home visiting as well as medical and other health disciplines, environmental, nutritional, housing and developmental** assessments.
- 5.5 Home visiting includes **identification and reduction** of obvious environmental hazards. Cleaning supplies should be provided and **cleaning services** delivered if the family is unable to do necessary lead clean-up.
- 5.6 **Other caregivers**, such as relatives or child care providers, are encouraged to participate in the assessment and attend medical appointments, with the family's permission.
- 5.7 The assessment is **updated on a regular basis**.

### **6.0 Each child has a written lead treatment plan that guides all treatment, therapies and services.**

- 6.1 All children served by the lead treatment team have a **written care plan** that contains all lead-specific services planned for that child, including: medical services, environmental and housing inspection, abatement, home visiting, discharge and relocation planning as needed, special educational supports and financial planning to ensure delivery of the needed services.
- 6.2 Families receive assistance in **understanding** all services and procedures contained in the lead treatment plan, including translation or interpreter services as needed.

- 6.3 The lead treatment plan contains **up-to-date information** on service needs, resources to be used and specific professionals or agencies that are responsible for providing services.
- 6.4 The lead treatment plan includes services that support the potential **growth and development** of each child.
- 6.5 Families receive a **copy** of the written lead treatment plan.
- 6.6 The lead treatment plan is **reviewed by all members of the lead treatment team** including families, environmental enforcement and other non-medical members of the team.
- 6.7 The lead treatment plan is **reevaluated**, quarterly or as frequently as required by the child's needs.

**7.0 Information concerning prevention, diagnosis and lead treatment resources is shared among all members of the lead treatment team, including family members.**

- 7.1 Families receive guidance about the **risk of lead to other members of the family**, especially children under age six and pregnant women.
- 7.2 Families receive **guidance about the potential impact** of lead poisoning treatment on all members of the family.
- 7.3 Families provide information on their **child's behavior, environment and health status** to other members of the lead treatment team.
- 7.4 The lead treatment team provides families with information on how to get a **wide range of services**, such as legal services, inspection and deleading, safehome programs, social services, mental health, self-help and family support groups, as needed.
- 7.5 Families receive **technical information** that explains and anticipates specific services, such as housing inspection, deleading and abatement.

**8.0 Families receive educational materials and information concerning lead poisoning and its impact on a child's individual growth and development, as well as poisoning prevention.**

- 8.1 Written materials prepared for families are available in the **primary languages** of the major population groups served.
- 8.2 Educational materials for families are **reviewed for accuracy and usefulness** by families who have received lead treatment services.

- 8.3 Families are **given extra educational materials** and are encouraged to share them with other care providers, such as day care, grandparents and other relatives.
- 8.4 Families have access to **written guidelines or standards** of care that are applied to lead treatment services.
- 8.5 Families receive help in **understanding the contents** of all written information.

**9.0 The lead treatment team recognizes the strengths as well as the needs of the child and family.**

- 9.1 **Family characteristics**, including culture, ethnic identity, and religious beliefs, are respected and used in the delivery of care.
- 9.2 **Family strengths and capacities**, such as carpentry, housekeeping, advocacy and organizational skills are recognized and utilized in reducing environmental hazards.
- 9.3 The team **coordinates appointments** among service providers in order to limit the family's travel time, waiting time and loss of work.
- 9.4 Assessments, inspections, abatement, health education services or treatments delivered in the home are planned to adapt to **family life activities**.

**10.0 The child and family receive timely developmental screening, periodic assessments and follow-up services to identify developmental needs or delays.**

- 10.1 Families receive **information and feedback** on results of all developmental assessments.
- 10.2 Families receive **guidance** from the lead treatment team about ongoing developmental needs of their child.
- 10.3 Timely **follow-up services**, including educational services, WIC, periodic lead screening and repeated developmental assessments are provided to the family after abatement and treatment are completed.
- 10.4 **Family support groups** are available to all families confronting lead poisoning.
- 10.5 Children receive lead treatment services at a pediatric facility that fits their age and **meets their developmental needs**.

**11.0 Continuity of care is maintained for the child when there are changes in health care delivery site, day care or living environment, care-givers, insurance or method of payment.**

- 11.1 The lead treatment team works with the family to plan for all **transitions** or changes, such as hospital-to-home, home-to-hospital, early childhood programs to school, or change in residence.
- 11.2 The lead treatment team works with families to **link their child's health services** with any community service providers who also care for their child, such as early intervention, day care or visiting nursing services.
- 11.3 **Care is not interrupted** when there are changes in staff on the lead treatment team, including residents and attending physicians.
- 11.4 Care is not interrupted when there are changes in the child's **insurance coverage**.
- 11.5 Care is not interrupted when a child **changes residence**.
- 11.6 The family is responsible for **notifying the team** of any changes in residence.
- 11.7 Children with elevated blood lead levels are **referred to appropriate local or state agencies** if they move out of the lead treatment team's jurisdiction.

**12.0 In-patient care for children with lead poisoning is well-coordinated with outpatient care.**

- 12.1 The care management **expertise of family members** is respected and utilized in the in-patient setting.
- 12.2 During in-patient stays, **one consistent staff person** is identified to communicate with families about the treatment plan for their child.
- 12.3 The lead treatment plan is followed or revised when a child becomes an **in-patient**.
- 12.4 The lead treatment team is notified of any **in-patient admissions** of children followed in the out-patient lead program.
- 12.5 Community-based providers such as environmental enforcement and home visiting services are **notified of any in-patient admissions** to ensure discharge to a lead-safe environment.

- 12.6 In-patient care physicians provide **summary discharge information** regarding in-patient care to the out-patient lead treatment team, as well as the child's primary care provider.
- 12.7 Hospital discharge planners are **knowledgeable about the special care coordination needs** of children with lead poisoning.
- 12.8 In the case of newly diagnosed children, hospital discharge planners ensure **appropriate referrals** to the out-patient lead services or case management services through local or state health departments.

## **ACCESSIBILITY OF CARE**

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### **13.0 Families receive lead prevention and treatment services at the local or community level whenever possible.**

- 13.1 Local **primary care providers** conduct lead screening and assessment for all children as required by applicable state regulations, Medicaid policy and health department recommendations.
- 13.2 Any family concerned about the risk of lead exposure for their child(ren) can receive **lead screening services at no cost to the family.**
- 13.3 **Care coordination** is provided to help families identify and access community-based services and coordinate those services with care delivered by the lead treatment team.
- 13.4 Services delivered at the community level are **reviewed by the lead treatment team** whenever the care plan is reevaluated.

### **14.0 Families receive written and verbal information regarding the full range of services available at the agency delivering lead prevention and treatment services.**

- 14.1 **Information about services and eligibility guidelines** for those services are clear and understandable.
- 14.2 Procedures for obtaining care during **evening and weekend hours** are provided in **writing** to families.
- 14.3 Families receive clear written information on **who to contact with questions** or how to get more information on lead poisoning treatment or services.

- 14.4 Families receive clear information about patient access to **research studies or innovative** therapies.

**15.0 Families receive assistance in addressing the financial implications of the lead treatment plan from the staff at the health care agency that delivers lead services.**

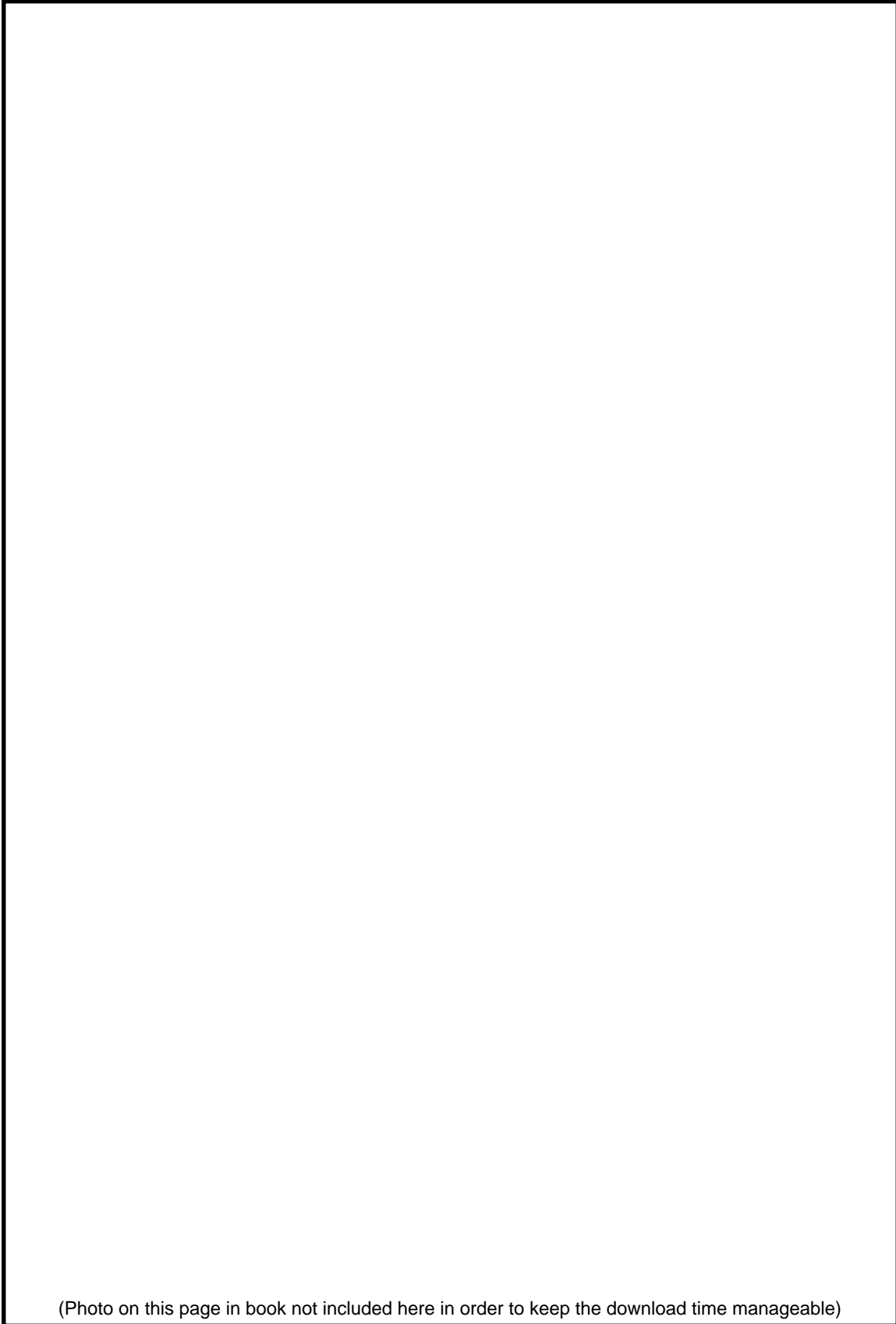
- 15.1 Families receive written and verbal information on how to apply for **financial assistance** for inspection, abatement, alternative housing or medical care for their child.
- 15.2 Families receive help in using all **insurance benefits, financial assistance, safehome and entitlement** programs for which they may be eligible.
- 15.3 The lead treatment team works with the family to **plan for the cost** of home, community-based or hospital care as early as possible, including planning for all major transitions such as hospital discharge or changes in insurance or housing.



## **SECTION II.**

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# **HEALTH CARE PROFESSIONAL AND TEAM CHARACTERISTICS**



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**S**ection II focuses on the behaviors and responsibilities of the professionals on the lead treatment team. Children with lead poisoning require expert, comprehensive services from a variety of professionals both within and outside the health care field. Services are often necessary for extended periods of time and professionals involved in the provision of services can be from distant sites and disciplines which are seldom involved in other health issues. This process of integrating care delivery has the advantage of enabling the expertise and skill of a variety of qualified professionals to come together to meet the child's medical, social and environmental needs. However, it also demands an ongoing commitment to close cooperation and coordination for both parents and professionals to ensure continuity and consistency over time.

Children with lead poisoning need many of the same community-based services as children with other special health care needs. These services are familiar to health care professionals. What differentiates lead poisoned children is the environmental aspect of their disease. Thus, the lead treatment team will also work with environmental inspectors, regulatory and enforcement personnel and members of the legal profession whose participation is essential to the delivery of comprehensive, effective care which reduces the child's exposure to environmental lead hazards. Furthermore, since the disease may significantly effect the family's finances and housing status, family-centered care must take into consideration the needs of other family members.

The standards in Section II address the resources, activities and responsibilities necessary for professionals when working as sole providers of specific interventions, as well as when working within the lead treatment team. Collaboration between the core team members based within the clinical setting and other team members in the community is complex and requires excellent communication and organizational skills in order to be effective. As the child grows and develops, the focus of care, and therefore the team's leadership, may change. Ongoing interaction between various team members, including opportunities for face-to-face contact is critical to assure that care is appropriate, community-based and responsive to the child's changing developmental needs. In addition, as our understanding of lead poisoning and the effectiveness of medical and environmental interventions evolves, team members need continued training to update skills.

The standards in Section II are grouped into three areas that focus on the maintenance of high levels of training, the lead treatment team's ability to provide and coordinate all necessary services and its capacity to respond to the specialized needs of the child and family:

- Education and Training
- The Role and Function of the Lead Treatment Team
- Team Responsiveness to Specialized Needs of the Child and Family

## **EDUCATION AND TRAINING**

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### **16.0 The professionals on the lead treatment team have the specialized education, experience, and credentials necessary to deliver quality care for children affected by lead.**

- 16.1 Health care professionals have the necessary **qualifications and training** to meet professional standards in the specific area of treating children with lead poisoning.
- 16.2 Health care professionals have **specific education and experience in pediatric settings** to understand issues related to early childhood development.
- 16.3 Health care professionals have specific education and training concerning the impact of lead poisoning on children, including **growth and development, learning disabilities, behavioral issues, hearing acuity and speech and language**.
- 16.4 Members of the lead treatment team are **familiar with the culture(s)** of the children and families served and receive training in cultural competence.
- 16.5 Professionals on the lead treatment team receive training on the concepts of **family-centered care**, with an emphasis on the individual needs of family and respect for the integrity of the family unit.
- 16.6 Professionals on the lead treatment team receive training on building effective **communication with families**.
- 16.7 Professionals on the lead treatment team receive training on the **impact of lead treatment intervention(s)** on the integrity of the family unit.
- 16.8 Professionals on the team receive training concerning the **role of state and local agencies** in housing inspections, abatement planning and other relevant services.

### **17.0 All health care providers serving children affected by lead maintain their current knowledge through specialized training and continuing education in order to deliver quality care.**

- 17.1 Professionals on the health care team are knowledgeable about emerging **standards of care, services and programs** designed specifically for children affected by lead.

- 17.2 **Other care providers** at the health care agency, such as in-patient nurses, phlebotomists, and laboratory and x-ray technicians, participate in **continuing education programs** about serving very young children affected by lead.
- 17.3 Professionals on the lead treatment team **participate in continuing education and training** through national conferences, training programs sponsored by state and federal Maternal and Child Health agencies, and locally available training opportunities.
- 17.4 Hospitals and clinics that provide specialty lead services to children and families provide up-to-date educational materials and continuing education programs to **primary care and local health providers** in the community concerning the prevention and impact of lead poisoning on young children.

## **THE ROLE AND FUNCTION OF THE LEAD TREATMENT TEAM**

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### **18.0 The lead treatment team, whether located in a hospital, community health center or primary care practitioner's office, includes all the appropriate professionals and family members needed to develop the child's lead treatment plan.**

- 18.1 The core members of the **lead treatment team** include: family members, physician, nurse or nurse practitioner and a community liaison. Interpreters are included as needed.
- 18.2 The lead treatment team has access to all the **necessary medical and health disciplines**, including audiology, child development, education, phlebotomy and laboratory services, nutrition, psychology, social work, speech and language therapy, and environmental enforcement and home visiting services, as needed.
- 18.3 The lead treatment team **coordinates care with community-based health and health-related professionals** (such as primary care physician, school nurse, visiting nurse, home inspectors, housing advocates, or home care providers) who provide direct services to the child or family.
- 18.4 The lead treatment team **coordinates its services with other community-based organizations** who work with families on issues related to lead. These may include information and referral agencies, transitional housing services, legal services, landlord associations, and other appropriate local or state agencies.

- 18.5 The lead treatment team includes **bilingual staff and/or interpreters** to ensure language translation and effective communication.
- 18.6 The **role and functions of staff members who visit families are defined**, with an acknowledgment of the importance of the privacy of the family.

**19.0 A designated member of the lead treatment team develops, coordinates and implements a written lead treatment plan for each child.**

- 19.1 The **lead treatment plan** contains all lead services, including: environmental education and housing inspection; abatement; home visiting; developmental assessment, screening and follow-up; as well as medical services.
- 19.2 The **team meets regularly** to develop, coordinate, and follow up on plans of care. The frequency of the meetings depends on the needs of the child and family.
- 19.3 There is a process that ensures **communication among team members** such as periodic meetings, telephone conferences, or sharing of copies of provider notes, with permission of the family. Sharing of information is limited to specific issues regarding lead treatment and supports coordination of care.
- 19.4 There is a process that ensures **communication with community-based providers** who are working with the family on issues related to lead.
- 19.5 **Family contributions** are included in the development of the lead treatment plan. Support is provided to families to facilitate their participation in the development of the plan, including support from parent-to-parent or lead advocacy organizations.
- 19.6 **Family members of the lead treatment team** may include foster families, extended family members or any other person who may serve as primary caregiver to the child.
- 19.7 A **copy of the lead treatment plan** is given to the family.
- 19.8 The lead treatment **plan is reviewed periodically**, at least quarterly, to evaluate outcomes of services provided, including all medications and other services prescribed, as long as lead levels remain elevated.

**20.0 A member of the lead treatment team is assigned to coordinate care for each child.**

- 20.1 A specific **coordinator** is identified for each child served by the lead treatment team.
- 20.2 An **initial assessment of family needs** is conducted by the coordinator to determine the need for services. Services should include those that could support the ability of the family to participate in the design and delivery of treatment for their child, such as translation, transportation or housing.
- 20.3 The coordinator promotes **on-going communication** among the members of the team, including the family, community-based physicians and other providers in areas such as housing, legal services, schools or day care.
- 20.4 The coordinator identifies, with family assistance, the name of an **emergency contact person**.
- 20.5 The coordinator assists the family to develop a plan for **financing specialized housing services and medical care**.
- 20.6 The coordinator **assists the family to identify community resources** to address housing issues.
- 20.7 The coordinator ensures that **in-patient care is coordinated** with out-patient plans and services.
- 20.8 The coordinator assures that there is **on-going communication between the family, other members of the lead treatment team and appropriate state and local agencies** as needed.
- 20.9 The coordinator **assists the family in scheduling appointments** so that time lost at school for the child or work for the family member is minimized.

**21.0 A member of the lead treatment team is designated to coordinate care with schools or other educational settings, such as Early Intervention, Head Start and pre-school programs.**

- 21.1 The lead treatment team provides families with **information regarding potential implications** of lead poisoning for educational performance.
- 21.2 **Written materials concerning educational implications of lead poisoning and available community resources** are provided to families, schools and child care facilities.

- 21.3 Information regarding an individual child's lead poisoning and the **potential implications for school or educational performance** is provided to the school nurse or other designated personnel at the family's request.
- 21.4 The lead treatment team provides **training or assistance to school personnel** to facilitate understanding of the educational implications of lead poisoning. This may include attendance at educational planning meetings or providing written materials.
- 21.5 **School nurses** are included in the community-based providers who receive up-to-date educational materials and notices of continuing education opportunities.
- 21.6 A member of the lead treatment team is available to **advocate for school-based services** when necessary.
- 21.7 Special attention is given to **linking health and education services** when a child's educational setting is changing, such as the transition from day care to school.

**22.0 Primary care providers cooperate with the lead treatment team to ensure comprehensive care to children affected by lead.**

- 22.1 A **designated primary care physician** at the local level delivers age-appropriate primary care in coordination with the lead treatment team.
- 22.2 The designated primary care physician takes responsibility for continued **monitoring of blood levels** and **developmental surveillance**.
- 22.3 The primary care physician **monitors changes in environmental factors** and assesses risk factors.
- 22.4 **Timely contact** (either written or telephone) occurs between the primary care providers and the lead treatment team following each patient visit and/or change in treatment protocols or medications.
- 22.5 Primary care physicians, as well as other providers, **make referrals** to appropriate private and public community services such as Early Intervention, Headstart, WIC and food stamps.

## **TEAM RESPONSIVENESS TO SPECIALIZED NEEDS OF THE CHILD AND FAMILY**

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### **23.0 Health services provided by primary care providers and the lead treatment team are based upon accepted standards and guidelines for practice.**

- 23.1 Primary medical care meets the guidelines of the **American Academy of Pediatrics**, including lead screening.
- 23.2 Lead screening services are consistent with **state laws and regulations**, Medicaid policy and health department recommendations.
- 23.3 Health services provided by the lead treatment team meet accepted guidelines for practice as defined by **professional boards and national organizations** and the most recent recommendations from the Centers for Disease Control and Prevention (CDC).
- 23.4 Care includes access to **up-to-date treatment and technologies** available for children with lead poisoning.

### **24.0 Professionals on the lead treatment team obtain and utilize information about the child's developmental level in their delivery of care.**

- 24.1 The lead treatment team obtains **information from the family** regarding the child's growth and development.
- 24.2 The lead treatment team provides ongoing **monitoring of developmental milestones**.
- 24.3 Families receive **information** about **developmental milestones** and are alerted to the need for ongoing monitoring.
- 24.4 The lead treatment team obtains consultations or makes referrals for **developmental evaluations** when needed, with the consent of the family.
- 24.5 Services and treatments are designed to meet **developmental needs and age** of the child.
- 24.6 There is communication between the lead treatment team and home visiting staff regarding **developmental progress** of the child.
- 24.7 Upon discharge from a lead treatment program, families are provided with information on **the developmental needs of their child that require continued monitoring**.

- 24.8 Upon discharge from a lead treatment program, **families receive training and guidance** on how to foster and support their child's continuing physical and intellectual development.

**25.0 Health care professionals on the lead treatment team inform families of available resources outside the health care agency.**

- 25.1 **Referrals** are made to educational, recreational, vocational or mental health agencies to meet the identified needs of family members.
- 25.2 Families receive information on **parent-to-parent and support services**, including those offered by advocacy and other voluntary associations.
- 25.3 Families are encouraged to identify **informal networks**, (e.g., grandparents, neighbors, friends) for family support.
- 25.4 The lead treatment team **makes referrals to appropriate private and public community services**, as needed, such as Early Intervention, Food Stamps, Head Start, WIC, lead safe/lead free daycare, housing options and medical insurance programs.

**26.0 The medical record used by the lead treatment team is accurately maintained and made available to the family.**

- 26.1 The medical record includes the **lead treatment plan** and documentation of all care delivered.
- 26.2 The medical record **documents training** received by the child and family to increase understanding of implications of lead exposure.
- 26.3 Summaries of **team communication and conferences** with the family are included in the medical record.
- 26.4 **Translation services** are available to families, if needed, to read and understand the medical record.
- 26.5 A health care professional is available at the agency to **explain the contents** of the medical record to families upon request.
- 26.6 Medical records are **legible, clear** and can be easily used.
- 26.7 The medical record includes a **check list or flowchart** of all services provided and all referrals made by the lead treatment team for each child and family.

- 26.8 Results of **housing inspections and abatement** plans are documented in the medical record.
- 26.9 The medical record **documents agencies and individuals** to whom lead treatment records have been made available.

**27.0 The lead treatment team and the agency consider cost in the planning and delivery of services.**

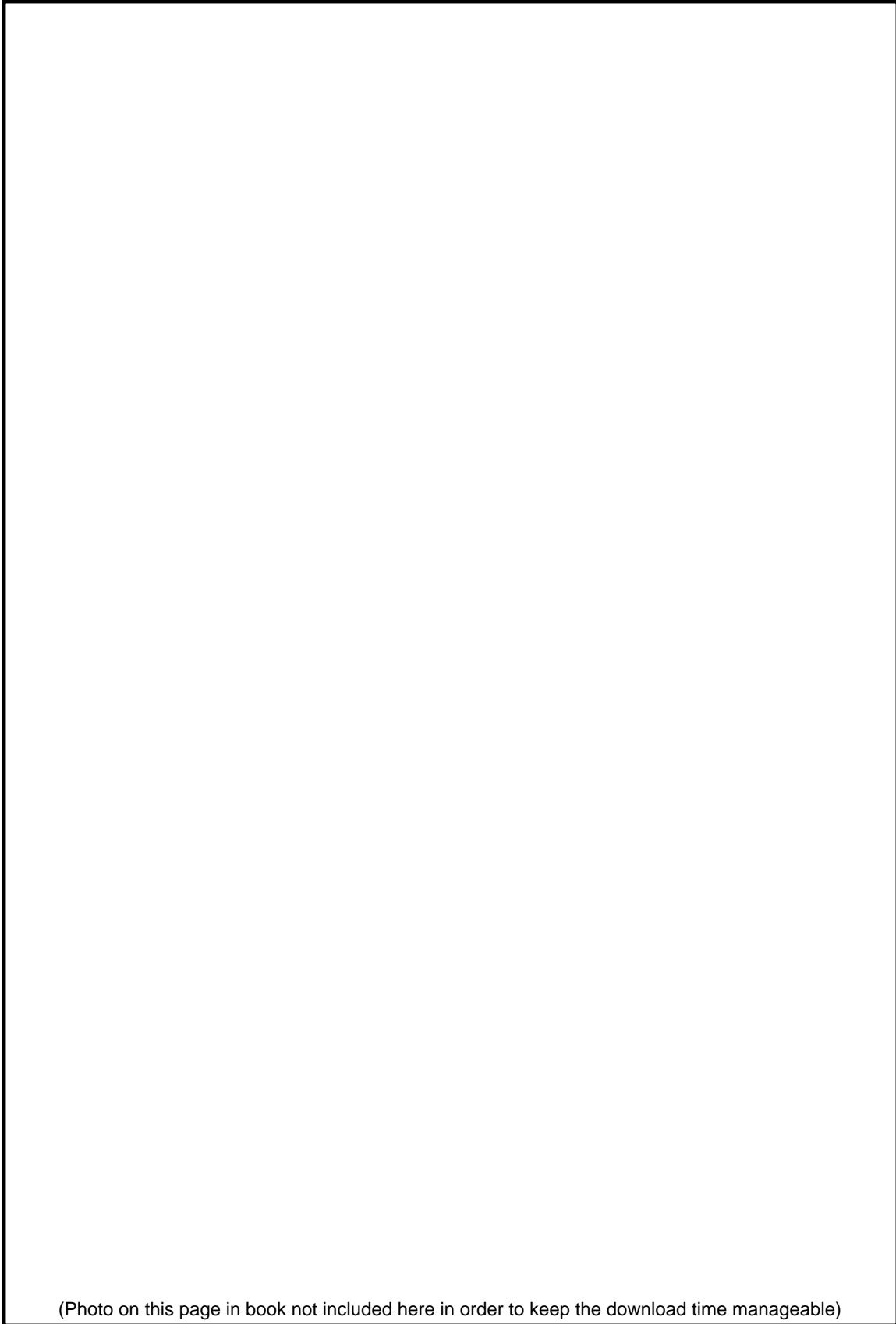
- 27.1 Members of the lead treatment team review the frequency of treatment and **eliminate service duplication** to control cost.
- 27.2 There is **ongoing communication** between the primary care physician and the lead treatment team to prevent unnecessary procedures.
- 27.3 Providers consider **cost for families and other payors** in selecting services, resources or special equipment.
- 27.4 Families receive **financial assistance and other resources** to implement plans for abatement.
- 27.5 **Non-traditional assistance** to families (i.e., cost of moving, security deposits, cost of lead hazard reduction supplies) is provided when necessary to implement a treatment plan.



## **SECTION III.**

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# **HEALTH CARE AGENCY OR FACILITY RESPONSIBILITIES**



The term *health care agency* includes the facility, organizational structure, operating policies and financial mechanisms that permit professionals to deliver safe, efficient and effective clinical care to children with moderately to severely elevated lead levels and their families. However, the agency's role extends beyond the delivery of services to an individual child with lead poisoning. Health care agencies have an additional responsibility to include lead poisoning in their prevention agenda by making information on the prevention of lead exposure available to all families with young children in their care. Agencies also have an obligation to be responsive to the needs of the communities which they serve and to support staff efforts to reach out to community organizations.

Examples of health care organizations that are included in the definition of *agency* are hospitals, tertiary care centers, health maintenance organizations, private specialty care clinics, community-based neighborhood health centers, free-standing lead centers, visiting nurse or home care agencies. *Agency* may also apply to private physician group practices that operate within a formal organizational structure rather than as a loosely affiliated group of providers. Networks or consortia of health and social service providers with one agency responsible for promoting quality care in all affiliated programs also fall within this definition of *agency*.

Supporting the health needs of lead poisoned children and their families is one of the most challenging tests of the health care agency, requiring the development and maintenance of a well-coordinated delivery system. The health care agency assumes responsibility for the quality of care delivered under its auspices and for creating a climate that is responsive to child and family needs, supportive of its personnel and organized in an efficient manner. To be most effective, the health care agency must guide and assist staff in providing comprehensive, family-centered care and actively support staff participation and collaboration with community-based organizations. In order to deliver high quality care, the agency forms cooperative relationships with other agencies, supports the expansion of knowledge through staff development and training and promotes the well being of its community through its teaching and research missions. The agency is also responsible for establishing overall goals and fostering the environment which allows these goals to be met.

Health care agencies are often governed by their own policy-making boards and may also have access to the advisory groups and agenda setting boards of other agencies. These connections can create opportunities to collaborate with other members of the community and can be used to facilitate families' access to decision makers. Agencies serving lead poisoned children and their families should seek consumer input at all levels of the organization and provide forums for families to participate in policy-making and program development.

Professional and staff activities within a health care agency are often constrained by guidelines, procedures and incentives established by payors or purchasers of care. The standards in Section III can be applied by purchasers or health insurers to guide contracting or support the development of family-centered policies.

The standards in Section III are grouped to reflect three areas:

- Agency Consideration of the Child and Family
- Staff Supports
- Administrative Effectiveness

## **AGENCY CONSIDERATION OF THE CHILD AND FAMILY**

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### **28.0 The health care agency that provides lead treatment services includes families who receive care within the agency on governance, policy-making and advisory boards.**

- 28.1 Governance, policy-making or advisory boards at the agency **ensure a consumer voice** by including families of children with special health care needs, such as those with lead poisoning, who are served by the health care agency.
- 28.2 Governance, policy-making or advisory boards include **community leaders, health care providers, and advocates for children's health** as partners in building responsive community-based lead services.
- 28.3 Families are **notified of opportunities** to participate on agency boards.
- 28.4 Families receive **supports** such as child care and stipends to facilitate participation.
- 28.5 Families are offered **training** in skills needed to participate on policy-making and advisory boards, as well as staff supports such as access to telephone, fax and word processing equipment to ensure full participation.
- 28.6 Policy-making or advisory boards **review agency services** in light of the community needs and the needs of families affected by lead.

### **29.0 Administrative operations in the health care agency are responsive to the needs of children and families affected by lead.**

- 29.1 The agency has a mission statement that includes a **commitment to family participation** at all levels.
- 29.2 The agency guarantees that all programs and services are available to children and their families **without discrimination**. Race, ethnic identity, language, religion, gender, sexual orientation, marital status, medical condition or method of payment do not affect access to care.
- 29.3 The agency has a policy for ensuring that children affected by lead receive care **regardless of the ability to pay**.
- 29.4 The agency ensures that families are **well-informed prior to giving consent** for any treatment or procedure.

- 29.5 The agency supports its staff in fulfilling their responsibilities for identifying, assisting, and reporting children at risk or potentially at risk for **child neglect or abuse**.

**30.0 The physical facilities of the health care agency are designed to meet the needs of young children and their families.**

- 30.1 All agency buildings are **accessible** for all users with physical or sensory impairments.
- 30.2 **Waiting areas and treatment rooms** are designed to accommodate family members while their child is receiving care and include easy access to telephones, infant changing areas and diapers.
- 30.3 Waiting areas and treatment rooms include **posters and other educational materials** on lead screening and treatment.
- 30.4 Furniture size, decor, toys and other waiting area diversions and reading materials fit the age and developmental level of the children being served, **especially the pre-school population**.
- 30.5 Physical settings throughout the agency are designed to provide **privacy and safety** for the child and family. Space is available for **confidential discussions**, and child care is available to allow families to concentrate on receiving information.
- 30.6 **Meeting rooms** are available to accommodate all members of the lead treatment team.
- 30.7 The health care agency has easy access to **public transportation** and provides **free parking** when needed.

**31.0 The medical diagnostic and therapeutic equipment used in providing care is designed to meet the needs of very young children.**

- 31.1 **Adaptations** are made in the equipment to accommodate the smaller size of young children and provide for their safety.
- 31.2 Personnel operating the equipment receive **adequate training** and understand the special needs of very young children.

## **STAFF SUPPORTS**

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### **32.0 The health care agency provides sufficient numbers and types of qualified staff to serve children affected by lead.**

- 32.1 **Staffing patterns** reflect the special needs of the children being treated, and include sufficient numbers of nurses, social workers, nutritionists, case managers, housing advocates and access to legal services.
- 32.2 Providers are recruited who demonstrate **understanding and sensitivity** as well as knowledge and skills needed to work collaboratively with families and children receiving lead services.
- 32.3 Efforts are made to **recruit and retain qualified** staff, including staff from minority or cultural and linguistic groups being served.
- 32.4 **Translation services and interpreters** are provided for the major populations served; efforts are made to facilitate translation for population groups that are present in smaller numbers.
- 32.5 **Interpreters** are trained and include the capacity to provide American Sign Language interpretation for hearing-impaired persons.
- 32.6 Sufficient numbers of **clerical and administrative support staff** are available to facilitate timely record-keeping and communication among professionals and families.

### **33.0 The health care agency provides an ongoing orientation and training program that supports provider readiness to deliver care to children affected by lead.**

- 33.1 Staff understand the agency's mission and the **family-centered approach** to care.
- 33.2 Staff have knowledge of **cultural issues** relevant to the population served.
- 33.3 Staff have knowledge of the **resources available** in the geographic area served, including the full range of housing inspection, abatement, safe-house and home visiting services.
- 33.4 **Professional resources and information on lead services** are available on-site and include relevant state and local health care regulations.
- 33.5 The agency provides **specific job descriptions** and regular performance reviews that include demonstrated competencies and abilities to provide lead services to young children and their families.

- 33.6 Relevant **quality assurance guidelines** and state health department regulations are available on-site.
- 33.7 The administrative leadership of the health care agency expects and supports staff to receive **ongoing education and training** specific to lead treatment services.
- 37.8 Families who have received lead treatment services participate in orientation and training programs to ensure a **consumer point of view**.

## **ADMINISTRATIVE EFFECTIVENESS**

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### **34.0 The health care agency has written policies regarding the medical record.**

- 34.1 The agency ensures individual **provider access** to the medical record at the time of each patient contact.
- 34.2 The agency ensures **family access** to the medical record.
- 34.3 The agency ensures the **confidentiality** of the medical record.
- 34.4 The agency has written policies to ensure that information from the medical record is released only with **family consent**.
- 34.5 The agency ensures **timely transfer** of medical record information when there is a change in site for clinical care.
- 34.6 The agency **informs families** when legal mandates require release of information from the medical record.
- 34.7 The agency provides **long-term storage** of medical records to ensure future access to information for health care decision-making.

### **35.0 The health care agency has a computer-based information system that provides efficient medical data management, record updating and information retrieval.**

- 35.1 The agency maintains information such as age, diagnosis and residence to describe the **population receiving lead services** for use by government agencies and advocacy organizations, while protecting confidentiality of individual children and families.
- 35.2 The organization provides an **annual report** on lead screening and follow-up services delivered.

- 35.3 **Management information** for clinics and programs providing lead services, such as budget information and utilization rates, are available to agency administrators and policy or advisory boards.
- 35.4 The agency has adequate **computer capability** to maintain the information system so that it is functional and useful to providers and families at the level of clinical care. Data should be stored in relational databases that can link information from multiple entries both as addresses or providers to an individual child.

**36.0 The health care agency has administrative, personnel and organizational policies that promote and support interagency coordination on behalf of children affected by lead.**

- 36.1 Agency personnel participate in **interagency committees** and projects aimed at improving coordination of services and program planning for children with lead poisoning.
- 36.2 **Collaborative agreements** exist that facilitate joint provision of services, coordination of care, case management and the sharing of information and resources between the agency and other agencies or facilities that serve this population. Examples include departments of health, Early Intervention, WIC, legal services, Head Start, child care programs, transitional housing and food stamp programs.

**37.0 The health care agency assumes responsibility for reviewing the quality of lead treatment care on a periodic basis.**

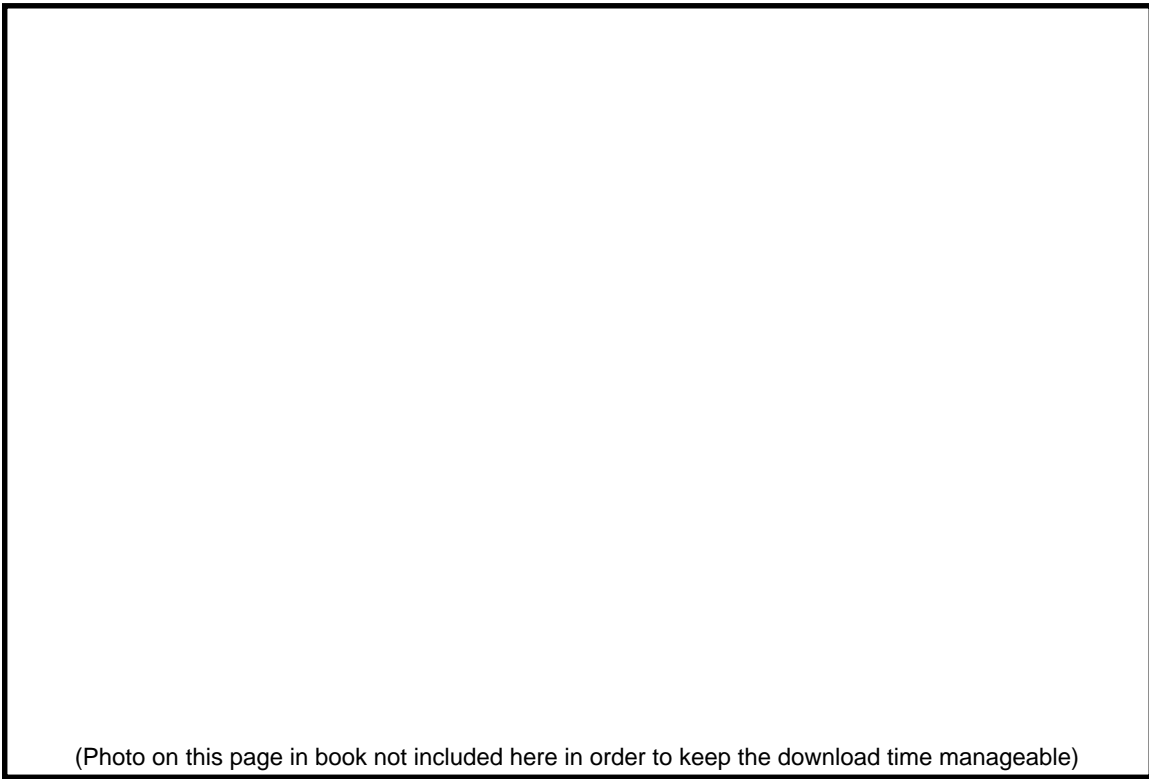
- 37.1 An interdisciplinary **quality assurance system** is well-staffed and includes a broad range of expertise, such as clinical care, environmental inspection and enforcement, and community providers to evaluate lead treatment services and overall program effectiveness.
- 37.2 The quality assurance system includes problem identification and planning for **quality improvement**.
- 37.3 The agency has a system of regularly-scheduled **peer review for lead treatment services**.
- 37.4 The agency has a system for obtaining **family feedback** on the quality of lead treatment services on a regular basis.
- 37.5 Findings from **quality assurance activities** are reviewed by the agency's governance and advisory committees and shared with families receiving services.

- 37.6 The agency promotes new and improved ways to **measure outcomes** so that delivery systems can be modified to better meet the special needs of this population of children and families.

## **SECTION IV.**

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# **HEALTH DEPARTMENT RESPONSIBILITIES**



Section IV gives special attention to the role of public health departments operated by state or local government. A clear vision and effective leadership are key elements in guiding the health care system's development on behalf of children and families. Leadership is needed to support and develop family-centered policies and to anticipate and plan for emerging needs. While lead poisoning prevention is a shared responsibility of many entities, state and local health departments with their expertise in providing health and social services, their role in developing and implementing public policy, and their legislative mandates, are uniquely qualified to assume a leadership role. Since leadership may vary by geographic area, with the state health department assuming these responsibilities in some states, while county or city health departments are more likely to serve these roles in others, Section IV uses a generic reference to *health department*.

Resource limitations and public demands for accountability have redirected the activities of many health departments away from providing direct services and toward the core public health functions of assessment, policy development and quality assurance. The new emphasis on these roles provides enormous opportunity for health departments at the state and local level to anticipate, plan, develop and maintain systems of care for children affected by lead and their families. As families who formerly received preventive health services in publicly sponsored health clinics enroll in managed care organizations, many health departments have assumed the role of purchaser of health services with new responsibilities for defining contractual obligations and monitoring health insurers' or other providers' compliance. State health departments, in particular, have the additional responsibility of developing and maintaining disease surveillance systems and providing feedback regarding changes in the risk status of populations to the professionals and agencies that serve the community. As units of local or state government, health departments are also in the position to convene inter-agency committees at the executive level working across organizational boundaries to provide training and to ensure that resources are available to implement policies in the wider community.

Section IV identifies the activities necessary for state and local health departments to assume a leadership role in building a quality health care system for children and families affected by lead. Fulfilling these responsibilities will require close collaboration with a broad range of public and private agencies as well as families. Partnerships are needed with health, housing and environmental inspection organizations, mortgage lenders, property owners and individual health care providers. When the local or state health department also has primary responsibility for environmental inspection and enforcement, capacity to build these partnerships, implement prevention strategies and support family-centered policies may be enhanced.

The standards in Section IV describe the state or local health department's responsibilities for planning, systems development, prevention, collaboration and promotion of family-centered care and are organized in the following four areas:

- Health Care System Development and Resource Allocation
- Health Promotion and Prevention
- Technical Assistance and Consultation
- Quality Assurance

## **HEALTH CARE SYSTEM DEVELOPMENT AND RESOURCE ALLOCATION**

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### **38.0 The health department conducts ongoing needs assessment activities to support planning and policy development on behalf of children affected by lead.**

- 38.1 A comprehensive needs assessment includes:
- a statewide **assessment of housing stock**,
  - a statewide **assessment of environmental risks**, such as industrial, water and soil, and
  - unmet health, educational, social, housing and financial **needs** of children affected by lead.
- 38.2 The health department uses multiple strategies for **identifying unmet needs** and gaps in services, such as public hearings and interviews or surveys of providers, families, advocates and community leaders.
- 38.3 The state health department works in cooperation with local health and housing authorities to maintain a **statewide data base** on housing inspections, lead abatements and lead safe housing by census tract.
- 38.4 The health department publicizes procedures for **identifying clusters of children** with lead poisoning and reports such clusters for epidemiological investigation for possible causes.
- 38.5 The health department collects population-based data and provides public reports on **health status indicators for children**, at least annually. The reports include numbers of children identified by screening as affected by lead exposure and those receiving case follow-up or environmental remediation.
- 38.6 The state health department, with assistance from other health and social service providers and consumers, develops **comprehensive, risk-based screening recommendations**.

### **39.0 The health department has a confidential child health data system that assists in planning for children affected by lead.**

- 39.1 **Families are informed** about purposes of data collection and planned uses.
- 39.2 All data that contribute to the state child health data system use **common threshold values** to define lead exposure, at-risk and lead poisoning in children.

- 39.3 All data sources are **integrated to create statewide** reports on incidence, prevalence and service utilization for children affected by lead.
- 39.4 The child health data system has the capacity to **make comparisons** with other local, state and national data.
- 39.5 **Other data systems** maintained by the health department, such as vital statistics, are periodically reviewed to maximize their usefulness for planning for prevention services or activities for children affected by lead.

**40.0 The health department collaborates with a broad range of families, health care professionals and advocacy groups on behalf of children affected by lead.**

- 40.1 The state health department creates an **advisory committee** to provide consultation and leadership in assessing the scope and effectiveness of services to children and families affected by lead.
- 40.2 **Standing committees** that advise the health department include family representatives, health care professionals and advocacy groups representing the interests of children affected by lead.
- 40.3 The health department actively seeks **consultation from a broad range of consumer and advocacy groups** such as: housing advocates, real estate groups, insurance professionals, community development corporations, as well as health care professionals and families caring for children affected by lead, when planning or reviewing specific policies or programs serving children and for primary prevention.
- 40.4 The health department **provides support to facilitate family participation** in advisory groups or as consultants. Support may include travel and child care reimbursement, honoraria, as well as training and ongoing staff support.
- 40.5 Family representatives on advisory groups reflect the **diverse cultural, racial and socio-economic groups** receiving lead treatment services.

**41.0 The health department assumes a leadership role in the development of integrated systems of care for children affected by lead.**

- 41.1 The state health department convenes a **statewide commission or leadership forum on childhood lead poisoning** that includes representatives from all state agencies with responsibilities that impact on children and families affected by lead. Examples of agencies include: Consumer Affairs; Environmental Protection; Banking; Insurance; Human Services; Housing; Education; Public Safety; Children, Youth and Families; and Medicaid.
- 41.2 The state health department works with **public and private providers and purchasers** of health services such as hospitals, Medicaid, Title XXI agencies and managed care organizations to develop a delivery system that is responsive to families caring for children with lead exposure.
- 41.3 The health department **establishes and supports a coordinated network of lead services** that is available for primary care providers to refer children and families for immediate assistance. This system includes access to necessary medical care through comprehensive lead treatment teams that include case management as well as legal services, home visiting, transitional housing, relocation assistance, rental subsidies and abatement assistance, as needed.
- 41.4 The health department supports **linkages between lead services and other community services** including WIC, Early Intervention, housing, child welfare, nutrition, transportation, and medical insurance.
- 41.5 The health department establishes an **emergency response protocol** to ensure rapid transfer to a safe environment for a child identified with high levels of lead.

**42.0 The health department advocates for allocation of scarce public resources on behalf of children affected by lead and for primary prevention of lead poisoning.**

- 42.1 The health department provides **public reports** on unmet needs, waiting lists and gaps in health, environmental or housing services for children with lead exposure or lead poisoning.
- 42.2 The health department provides information to other public and private agencies regarding **priority health care, housing needs** and lead-safe child care settings for children affected by lead.
- 42.3 Objective **eligibility criteria** are applied to the distribution of publicly supported services.

- 42.4 Objective **evaluation criteria** are applied to publicly supported programs and services, such as grants to support housing repair and development, case management and home visiting, to ensure efficient and effective use of public funds.
- 42.5 The state health department ensures that federal and state training grants respond to the need for **appropriately trained personnel**.

**43.0 The health department uses resources to fill identified gaps in the health care delivery system for children affected by lead.**

- 43.1 Special attention is given to **services not adequately supported** in the private sector, such as enhanced care coordination/case management, respite care, nutritional assessment and intervention services, family support services, parent education, transitional housing and environmental inspection.
- 43.2 The health department works with other purchasers of care, such as the state Medicaid program, to **advocate for inclusion of a full range of needed benefits**, including enhanced care coordination/case management.
- 43.3 Special attention is given to implementing **alternative screening strategies** for high risk geographic areas.
- 43.4 The health department ensures that **enhanced care coordination/case management** is available at the community level to families caring for children with lead exposure or lead poisoning.
- 43.5 When state health department funds are used temporarily to fill gaps in services, planning occurs to design **alternative long-term methods** of service delivery.
- 43.6 The health department funds **innovative projects** to enhance care coordination and quality of care for children affected by lead, and encourages replication when they are successful.

**44.0 The health department ensures that information and referral services are developed to support prevention efforts and to assist all health care providers and families caring for children affected by lead.**

- 44.1 An information and referral system is **well-publicized and accessible** in local communities and in all hospital and health care settings.

- 44.2 The lead information system includes **available health and related services** such as lead-safe child care settings, home visiting programs, parent support groups, updated treatment information, environmental inspection, abatement, safe housing and legal services, and location of specialty medical services for children affected by lead.
- 44.3 The lead information system is **continually updated**.

**45.0 The health department provides technical assistance and training to families, providers and educational institutions on childhood lead poisoning prevention and treatment.**

- 45.1 The health department supports or provides training and educational programs for **parents, health and education professionals and child care providers** on new and emerging issues in the care of children affected by lead.
- 45.2 The health department supports or provides ongoing education to **primary care providers**, such as pediatricians, who conduct lead screenings and care for children affected by lead.
- 45.3 The health department provides technical assistance to **local school systems, education personnel and child care providers** concerning childhood lead poisoning prevention and treatment and the implications of lead poisoning for learning and social development.
- 45.4 The state health department provides technical assistance and advice to professional schools and training programs to include content on childhood lead poisoning in their **curricula**.

**46.0 The state health department periodically reviews state mandates for health services to ensure that they address the special needs of children affected by lead.**

- 46.1 State regulations for hospitals, including discharge planning guidelines, support **family-centered care** and reflect the needs of children and families affected by lead.
- 46.2 State mandated child **screenings and immunizations** are periodically reviewed to ensure that they address the unique needs of children affected by lead.

## **HEALTH PROMOTION AND PREVENTION**

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### **47.0 The health department provides leadership in establishing programs to prevent exposure to lead by children and reduce the long-term health effects of lead poisoning.**

- 47.1 The health department provides or supports a full continuum of modern **prevention and intervention** services.
- 47.2 The health department supports **public education** that reinforces lead-safe health practices and essential property maintenance practices to reduce exposure to lead.
- 47.3 The health department ensures access to services for the **early identification of lead poisoning** in children.
- 47.4 The health department promotes **family environmental education** and other community-based prevention efforts.
- 47.5 **Educational materials** and programs regarding lead poisoning prevention are developed and widely disseminated to provide education and support to **primary care providers** in their role of early detection and intervention.
- 47.6 The state health department periodically reviews existing state **housing regulations and mandates** to assure the availability of lead-safe housing for children and families.
- 47.7 The health department works with state or local housing authorities and private building contractors to **eliminate unsafe renovation practices**.

### **48.0 The health department provides leadership in establishing programs that prevent complications of conditions caused by lead exposure in children.**

- 48.2 Standards for assessment, intervention and monitoring the **nutritional status of children** with lead exposure are developed and disseminated through statewide training and outreach efforts, including WIC and food stamp programs.
- 48.1 The health department supports the development of models that **assure a smooth transition** from services provided in lead clinics to early intervention programs and to schools.

- 48.3 The health department supports educational efforts that reinforce the importance of **early intervention and comprehensive care** for children with lead exposure and their families.
- 48.4 The health department develops systems to **facilitate the sharing of data across programs** that respect family privacy and rights of confidentiality.

## **TECHNICAL ASSISTANCE AND CONSULTATION**

### **49.0 The health department provides technical assistance and consultation to a range of public and private agencies to capture opportunities for prevention and enhance services for children with affected by lead.**

- 49.1 The health department provides **access to clinical expertise** to assist agencies and institutions in care coordination/case management and service delivery. This may include managed care organizations, primary care providers, multi-disciplinary specialty care teams, insurance companies and legal assistance programs.
- 49.2 The health department assists agencies that conduct day care licensing, foster parent recruitment and training, and lead abatement services as they address emerging needs and **plan for services** for children affected by lead exposure and lead poisoning.
- 49.3 The health department provides consultation to a range of public and private agencies on **lead-safe housing issues**.
- 49.4 The health department provides **technical expertise to assist housing redevelopment agencies** in creation of lead-safe, affordable housing for families.
- 49.5 The state health department assists other state agencies and local organizations such as departments of human services, environmental protection, housing authorities and community development corporations as they address **housing and environmental issues** that impact lead safety for children.

**50.0 The health department works with the education and child care system to support the integration of children with lead poisoning into school and child care settings.**

- 50.1 State departments of health and education work together in the **development of policies** that support adaptation of school settings for children with lead poisoning.
- 50.2 The health department **provides guidelines and standards** for educational assessment and follow-up for children affected by lead exposure and lead poisoning.

**51.0 The state health department works with providers of health care services to broaden their understanding of the unique health care and social service needs of children affected by lead.**

- 51.1 The state health department improves **access to health insurance** by addressing issues such as ensuring continuity of coverage, benefits for case management services, and reimbursement of care delivered across geographic boundaries for children affected by lead.
- 51.2 The state health department seeks **adequate reimbursement** for a full range of services, including enhanced care coordination and environmental inspection services for children affected by lead.
- 51.3 The state health department consults with **purchasers of health care services**, including Medicaid, on the need for flexible and comprehensive benefits to avoid hospitalization. These include coverage for: home care, long-term and school-based care, mental health and behavioral services, nutritional services and products, and interim lead abatement cleaning measures, transitional shelters and temporary housing.

## **QUALITY ASSURANCE**

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**52.0 The health department uses standards and guidelines to promote quality medical care and the assurance of safe housing for children affected by lead.**

- 52.1 Standards pertaining to the **quality of lead screening, confirmation of diagnosis, risk assessment and intervention** are periodically reviewed, revised and widely disseminated.

- 52.2 Standards pertaining to the **quality of lead inspection, abatement and property management** are periodically reviewed, revised and widely disseminated.
- 52.3 The state health department **develops and/or utilizes existing standards and guidelines** that promote individualized, family-centered, community-based services for children affected by lead exposure and lead poisoning.
- 52.4 Procedures exist for **disseminating the standards** to a broad range of families, professionals and advocacy groups.
- 52.5 Standards and guidelines are periodically **reviewed and revised** by a broad range of users including families.
- 52.6 **Public acknowledgment** is given to those professionals, teams, centers or programs that meet identified standards or guidelines.
- 52.7 Public acknowledgment is given to **communities and organizations** that renovate or establish **lead-safe day care settings and low-income housing**.

**53.0 The state health department has a quality monitoring system in place to evaluate contracts, grants and direct services to ensure that they are responsive to children affected by lead and their families.**

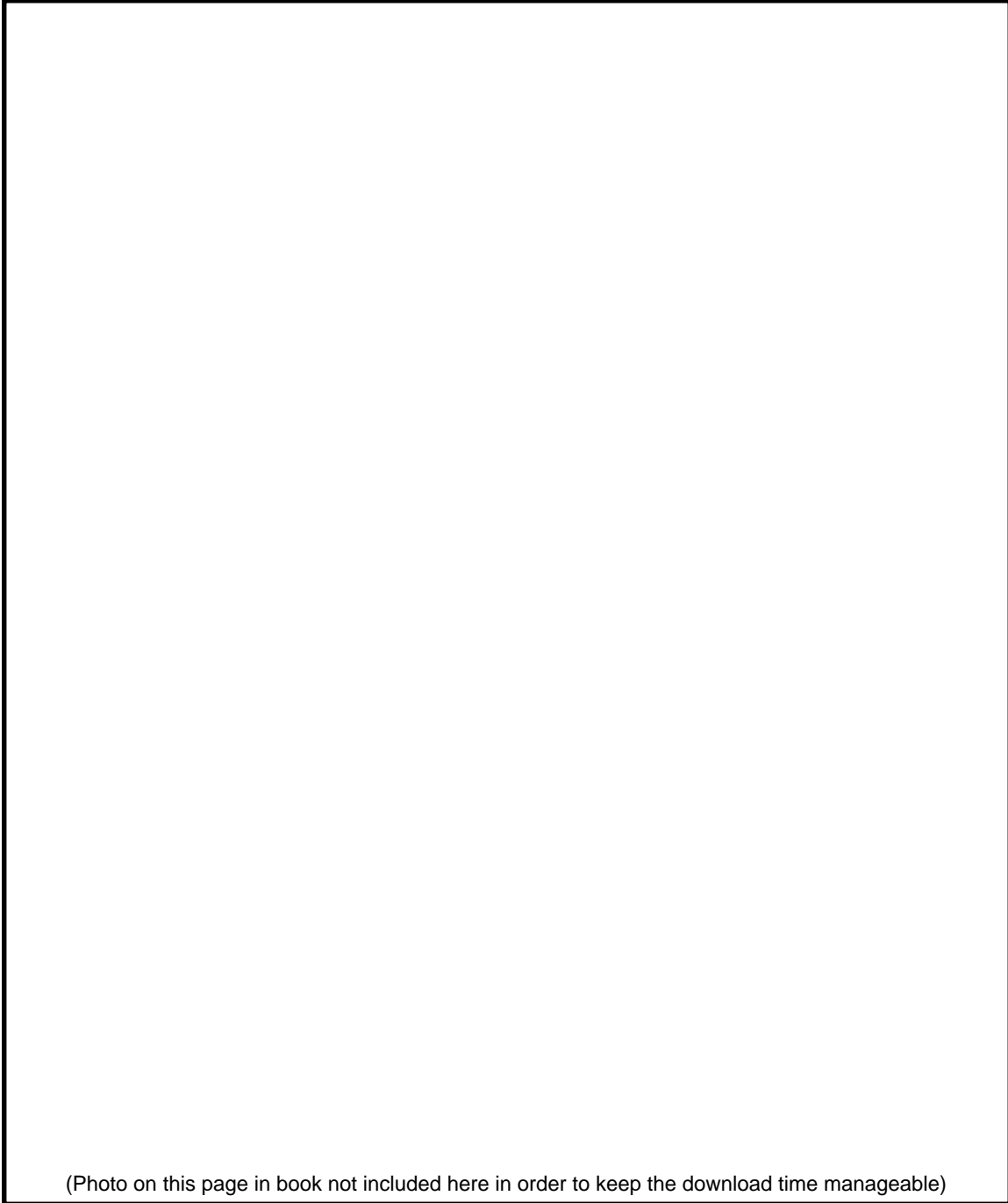
- 53.1 The state health department **monitors the attainment** of its own identified goals and objectives.
- 53.2 The state health department has an **internal audit system** for monitoring the use of funds in purchased or contracted services.
- 53.3 The state health department **monitors compliance of publicly funded programs** with existing standards and guidelines.



## **SECTION V.**

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# **GUIDELINES FOR PREVENTION AND COMMUNITY SUPPORT**



The standards in the four previous sections focus on the delivery of and support for high quality health care to children affected by lead and their families. However, successful implementation of these standards requires a coordinated effort involving many segments of society and reaching well beyond health care providers or agencies. Although many of the activities, roles and guidelines described in these sections are related to prevention efforts, prevention is often not the primary reason for undertaking them. Section V is designed to recognize the social context of both intervention and prevention strategies. This section asks users to expand their thinking to consider strategies for building safe and healthy communities for growing children; to identify community characteristics and values that shape family life, affect health status and influence a community's ability to implement policies which reduce environmental contamination. Responsibility for these activities may rest with governmental or voluntary organizations or require collaboration across multiple groups. Nowhere is this more apparent than at the intersection of the health care and housing systems. The same infrastructure necessary to ensure high quality care for children affected by lead exposure and their families, underlies a community's capacity to prevent children from becoming lead poisoned in the future. Section V challenges everyone to identify activities where they may join families and communities to increase public awareness and primary prevention of childhood lead poisoning.

Individuals define *community* in many ways. Definitions often shift to accommodate differing needs or purposes. Families may define their communities based on the type, intensity and frequency of their needs. For example, a family's educational community may correspond to the local school district, whereas, the community from which health care services are received may cover a wider geographic area. For some families, their health community may extend a considerable distance to include sites where specialty services are delivered, or it may be defined by the vast array of informal resources utilized in rural settings.

Families have differing expectations of what services need to be present in their immediate community. Generally considered important and included are the following: primary care, dental services, information and referral, nutrition, care coordination/case management, a school system which is responsive to children with special developmental and behavioral needs, recreation, respite care, family supports, public awareness efforts, effective advocacy and safe and sanitary housing.

Culturally-specific values may also influence how a family defines its community. Such values may include the importance of sharing a common language, respect for religious beliefs, or a shared concept of family roles and responsibilities. In some instances these values may supersede geographic proximity in defining community, and families may seek critical services by choice from a broader geographic area or region.

Section V is organized into three major areas where activities must take place in order to support a system of quality health care, integration of children with special health care and educational needs and their families, and creation of a reservoir of lead-safe housing. Because of the shared nature of responsibility for these activities, the goal of this section is to provide guidance to groups and individuals rather than establish standards. Section V offers a set of guidelines to assist families, professionals, agencies and advocates for children to seek high quality services while building the political will and fiscal resources necessary for effective primary prevention to reduce lead exposure and lead poisoning in childhood.

The three areas in Section V include:

- Public Awareness and Family Support
- Community Program Planning and Prevention
- Advocacy Efforts

## **PUBLIC AWARENESS AND FAMILY SUPPORT**

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For families of lead poisoned children, lead exposure is often only one of a number of serious threats. The environmental nature of the disease, the difficulty in obtaining lead-safe housing and the expense of lead hazard reduction and control measures overwhelm many families' coping mechanisms. Families who have similar issues can provide each other with mutual support and understanding and share information on available services and coping strategies.

In many other chronic illnesses, family support groups have become institutionalized and have expanded their role to include political action and advocacy. These family and consumer groups have also increased their activities in the area of public education and increased community awareness. Families of lead poisoned children also have much to offer in the way of prevention education for the larger community. The guidelines in this section define the components of a quality public awareness and family support system. The goal of public awareness efforts is to increase the community's understanding of the causes and consequences of childhood lead poisoning and enhance the community's capacity to develop a reservoir of lead-safe housing. These are complemented by family support efforts which assist families in accessing mutual support, information and services for their child and other family members.

### **54.0 Public and private organizations in the community sponsor and support activities that increase public awareness of childhood lead exposure and lead poisoning.**

- 54.1 Institutions such as schools, universities, libraries, museums, hospitals, health centers and social welfare agencies initiate **lead poisoning prevention awareness programs** for children and adults, such as recognition of Lead Poisoning Prevention Week.
- 54.2 Members of the community are recruited to **participate in public awareness and outreach programs**, such as door-to-door screening, public education events, and other activities, to increase community awareness of the risks of lead exposure.
- 54.3 Members of the community are **recruited and trained as volunteers** to assist in programs that serve children with lead poisoning.
- 54.4 **Volunteers** who serve in lead education and treatment programs are identified and recognized.
- 54.5 Exemplary **public education programs** are recognized.

- 54.6 Public service announcements, community cable television programs, local health fairs and cultural events (e.g., films, art exhibitions, and theatrical productions) are utilized to increase **public awareness** about lead exposure and lead poisoning.

## **55.0 Community-based health and education agencies provide training on lead poisoning prevention and the impact of lead poisoning.**

- 55.1 **Training concerning prevention of lead poisoning** is made available to families in community settings such as libraries, schools, churches, health centers and community-based lead poisoning prevention centers.
- 55.2 **Training sessions** are developed for building inspectors, realtors, housing managers, property owners, building tradesmen, contractors, lawyers, bankers, teachers and other professionals in the community and include information on their roles and responsibilities.
- 55.3 Training for persons who work with children in the community, such as **day care providers, early childhood educators and teachers**, includes information on impact of childhood lead poisoning, the need for routine medical follow-up for identified children, and appropriate educational interventions.
- 55.4 Training includes information on: **defining lead poisoning, tips for prevention, resources for prevention and long term impact of childhood lead poisoning.**

## **56.0 Local employers, businesses, civic organizations and foundations provide leadership and invest in prevention and treatment of lead poisoning.**

- 56.1 **Corporate giving and voluntary contributions** are targeted to benefit children with lead exposure in the community.
- 56.2 **Private organizations and charities** recognize and address lead poisoning as a priority child health issue.
- 56.3 Personnel policies of local employers are **supportive of families** caring for a child with lead poisoning, including use of family leave benefits to manage lead poisoning and lead abatement.

- 56.4 Employment practices **do not discriminate** based on the special health care needs of employees or their family members, such as the need for time off from work to accomplish housing abatement or relocation.
- 56.5 Employer sponsored **health insurance plans** are responsive to the needs of children with lead poisoning and **include enhanced case management services** and environmental inspection services.
- 56.6 Local businesses and civic organizations **encourage volunteerism** among employees to support the prevention and treatment of lead poisoning.

**57.0 Family support programs and parent-to-parent networks are promoted and financed.**

- 57.1 A full range of **support services are available in the community**, such as lead-safe babysitting/day care, transitional housing, transportation, and advocacy services to support families caring for children with lead poisoning.
- 57.2 Parent-to-parent networks **link families** to advocacy groups, health and housing-related services.
- 57.3 **Parent-to-parent networks** are encouraged and widely publicized.
- 57.4 Parent-to-parent networks are **locally-based**.
- 57.5 Families receive **respite care services** to assist with lead abatement, relocation and housing adaptations.

**58.0 Families have access in their community to updated information and referral services for lead poisoning.**

- 58.1 Statewide information and referral services are **widely publicized** and available at **no cost**.
- 58.2 A **comprehensive range** of child health and family support services are included in the information and referral services.
- 58.3 Health centers and other providers of **routine pre-natal care** include information on lead poisoning prevention.
- 58.4 **Community-based agencies** that serve children and families, such as visiting nurses associations, early intervention programs, and outreach programs, have the **capacity to provide information and referral services** for lead poisoning services.

## **COMMUNITY PROGRAM PLANNING AND PREVENTION**

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Many public and private organizations provide services to children, youth and families. While some of these groups address community needs in general, more often they focus on specific areas such as medical care, education, mental health, social services or safe and affordable housing. Effective community program planning and prevention of lead poisoning requires cooperation across such diverse organizations.

Definitions of target populations, operating procedures, geographic catchment areas, databases and information vary among service providers and agencies. Controlling and eliminating residential lead hazards requires the commitment and resources of partners in both the private and public sectors. Differences in the mission, goals and organizational culture across public and private agencies can contribute additional barriers to effective needs assessment and planning at the community level.

Because the needs of children and families affected by lead fall within the purview of many agencies, families face the often difficult task of integrating multiple services. Coordinated planning and program development are needed at the national, state and community level to facilitate delivery of care. These activities require close collaboration, ongoing consumer and professional involvement, and open communication as described in the following guidelines.

### **59.0 Families and other stakeholders concerned with lead exposure or lead poisoning are represented on a broad range of planning and policy boards at the local level.**

- 59.1 Community organizations, such as lending institutions, hospitals, neighborhood health centers, United Way, mental health centers, YMCAs, civic groups, non-profit housing organizations, school-based organizations, and housing shelters, **recruit family and provider representatives concerned with lead exposure and lead poisoning.**
- 59.2 High risk communities establish a **community task force** with local governmental support that is focused on the issue of lead exposure and lead poisoning.
- 59.3 **Family representatives** are drawn from a variety of child/family advocacy and support groups and are broadly representative of diverse cultural and socio-economic groups.
- 59.4 **Provider and agency representatives** are drawn from a broad range of community organizations, such as housing, education, health, social and legal services.

- 59.5 Community planning and policy boards provide training to family representatives and other board members to **build partnership skills**.
- 59.6 **Financial supports**, such as stipends for day care and honoraria, are provided to family representatives to facilitate their participation.

**60.0 Needs assessment activities occur at the community level to improve program planning for children and families affected by lead exposure and lead poisoning.**

- 60.1 Multiple strategies for **identifying unmet needs** and gaps in resources are utilized, such as public hearings, focus groups, and surveys of providers, families, and community leaders. Additional resources such as geographic informational mapping systems (GIS) are also utilized.
- 60.2 Needs assessment strategies identify child and family service needs in **multiple service areas**, such as education, recreation, social service, housing, legal and health services and education.
- 60.3 Needs assessment activities include **outreach efforts** to identify individual children in need of services. These efforts should include **multi-cultural and multi-lingual strategies** that address the cultural and linguistic groups in the population of the community.
- 60.4 **Health insurers** participate in outreach and needs assessment activities at the community level.
- 60.5 **Information generated at state and local levels should be available** to organizations and advocacy groups in the community that are concerned with lead exposure and lead poisoning.
- 60.6 Information generated by needs assessment activities should be **widely disseminated** to WIC and other pre-natal care and nutrition service providers.

**61.0 Public, private, and voluntary organizations coordinate their program planning efforts to ensure that families affected by lead exposure and lead poisoning experience integrated services.**

- 61.1 Planning for local health care services reflects the **specialized needs of children affected by lead exposure and lead poisoning**.
- 61.2 Community organizations ensure **continuity of care** during major transitions in service delivery systems in the community.

- 61.3 Community organizations, such as Head Start, Early Intervention, neighborhood health centers and agencies, and visiting nursing services, coordinate their efforts to provide **unduplicated home-based intervention** services.
- 61.4 Community organizations, such as health and education programs, social service agencies and housing agencies, ensure access to **transportation services** to families when they have to find new housing because of lead exposure.
- 61.5 Families of children with lead poisoning have **access to care coordination services**.
- 61.6 Services provided by each community agency are clearly **identified and publicized**. Inter-agency-agreements are developed to implement joint programs.
- 61.7 **A comprehensive lead poisoning prevention center** provides leadership in planning and coordination of services in high risk communities.
- 61.8 **State sponsored health services**, such as immunizations, lead, TB, AIDS and STD screenings, and follow-up services, are coordinated to avoid duplication of home visiting and other services.

## **62.0 Public and private agencies work together to build effective primary prevention programs at the community level.**

- 62.1 Community-based health care agencies and health insurers **identify effective sites and strategies for lead screening services**, including local WIC programs.
- 62.2 **Community housing agencies** address the issue of lead exposure and lead poisoning in housing code regulations and Section 8 housing protections.
- 62.3 Community-based agencies work together to **expand the definition of affordable housing** to include “lead-safe and affordable housing.”
- 62.4 Community-based housing agencies and lending institutions fulfill their **responsibilities within P.L. 102-550, Title X: The Residential Lead- Based Paint Hazard Reduction Act of 1993**, in areas such as property transfer notification.
- 62.5 **Educational materials** on the prevention of lead poisoning are distributed in all real estate rental or sales transactions.
- 62.6 Community-based lending institutions and mortgage holders **adapt existing loan products to finance abatement**.

62.7 Lead-based paint hazards are addressed in **city and state consolidation plans as mandated under Title X**.

62.8 Local governments work with state agencies to ensure that knowledgeable, trained and **certified lead inspection, abatement and follow-up services** are available and affordable in the community.

### **63.0 Local schools and pre-school programs recognize and address the implications of lead exposure or lead poisoning on the ability of affected children to perform in school.**

63.1 Head Start, pre-school programs and local schools provide services to young children in **lead-safe environments**.

63.2 Head Start, pre-school programs and local schools **include information on history of lead exposure or lead poisoning** in intake screening and other educational records.

63.3 **Head Start, pre-school programs and local schools provide developmental assessments** to children affected by lead exposure and lead poisoning on an ongoing basis.

63.4 Local **parent councils** that are established to identify special education program needs and monitor compliance include parents of children affected by lead exposure and lead poisoning.

63.5 **Public schools provide training programs** that enable educational staff to understand the impact of lead exposure and lead poisoning on learning.

### **64.0 Local schools ensure that children affected by lead receive the necessary health supports to participate in school.**

64.1 Children requiring intermittent hospitalization receive timely and age appropriate **home or hospital-based** education.

64.2 Policies are in place to ensure that needed **physical and mental health services are delivered in the schools** to children affected by lead exposure and lead poisoning.

64.3 Schools ensure that school personnel receive necessary **training** or assistance to provide the necessary health services.

64.4 Schools use **individual educational plans** to ensure that children affected by lead receive reasonable modifications in their learning environments when needed.

## **ADVOCACY EFFORTS**

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Advocating for children is a special responsibility. Children, because of their age, developmental level, and legal definition, require others to speak for them, especially when their rights or interests are at risk. Traditionally, parents, guardians, public officials, and interested citizens at large have assumed the child advocacy role. These advocacy efforts have often stemmed from the needs of a specific child and family and broadened to collective efforts on behalf of many children with similar needs.

Parents who advocate for groups of children add these unpaid activities to their on-going parenting responsibilities. Advocacy requires skills that are effective in the public arena as well as financial resources for implementation. Fortunately, recent legislative mandates in the field of education have encouraged and supported the development of such skills, which may be transferred to health care. A broad range of necessary and available activities permits advocates to choose a comfortable level of participation. Some may write letters of support to legislators or testify at legislative hearings, others may wish to serve on local, state or national policy-making committees.

Professionals, like family members, have in-depth knowledge of the issues relating to children and families affected by lead. This knowledge must be transmitted to a broader audience in order to contribute to effective advocacy and expanded public awareness. Professionals are encouraged to join with parents in analyzing and publicizing public policy issues that relate to children and families affected by lead.

Parents, professionals, and other interested citizens have often formed organizations along disorder and disease specific lines. While these groups do perform important mutual support and education activities, they also advocate for a relatively small population of children and families. Coalitions among these groups can strengthen advocacy on behalf of all children with special health care needs.

The following guidelines identify ways in which advocacy efforts can be organized to ensure that the interests of children affected by lead are represented and that primary prevention activities are widely supported.

### **65.0 Individual child advocacy services are available and accessible in the community.**

- 65.1 Each community provides a **coordinated system** to ensure access to information on advocacy resources for housing, legal and educational services.
- 65.2 **Families receive training and support** to become effective advocates for their children.

- 65.3 Community agencies, including health care delivery sites, **publicize resources** for individual child advocacy.
- 65.4 Community agencies, including health care delivery sites, **provide information to their staffs** concerning the availability of advocacy services for families.
- 65.5 Individual child needs are aggregated to assist in identifying areas for **collective advocacy at the community level**.
- 65.6 Community-based advocacy data are aggregated at the state level to **enhance state-based advocacy** efforts. Aggregated data are **distributed** to local communities and advocates.
- 65.7 Advocates for children **monitor and report on compliance with mandated services**, regulations, and standards of care.
- 65.8 Local statutes **prohibit discrimination in housing against families** with children.

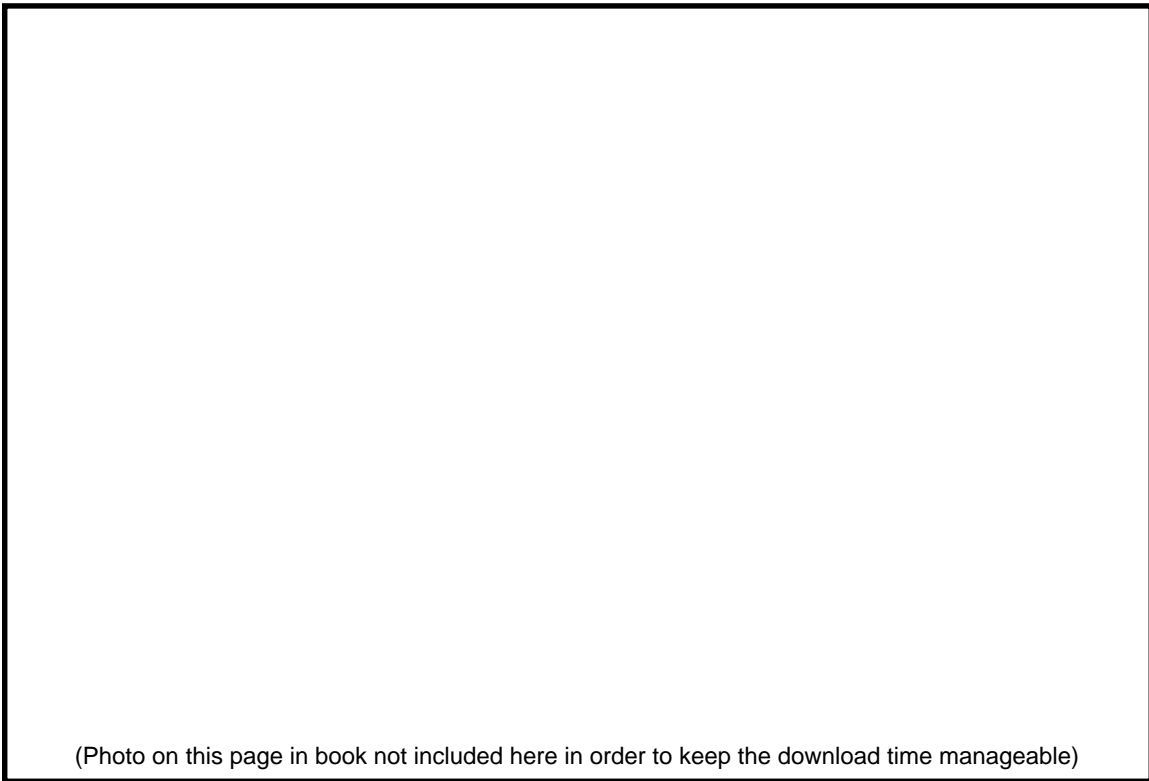
**66.0 Child advocacy groups receive support for their efforts on behalf of children and families affected by lead exposure and lead poisoning.**

- 66.1 Community-based foundations, local government and other funding sources **support child advocacy groups**.
- 66.2 Community-based advocacy groups have opportunities for **training** to develop effective advocacy skills.
- 66.3 Advocates **communicate with public officials** and legislative bodies regarding needs of children and families affected by lead exposure and lead poisoning.
- 66.4 Local advocacy organizations include families, and have **leadership roles in developing policies and procedures** concerning lead exposure and lead poisoning at the community level.
- 66.5 Local advocacy organizations participate **with state and federal agencies in developing policies and procedures** that affect children and families affected by lead exposure and lead poisoning.

**67.0 Coalitions between parents, professionals, local governments and other advocacy groups are formed to promote collective action at the community level to promote effective treatment for children and families affected by lead.**

- 67.1 Communication systems are developed to support **information exchange and collaboration** among the various advocacy and professional organizations in the community.
- 67.2 Advocacy groups **form coalitions with professional organizations** to lobby for needed policy changes relating to children and families affected by lead.
- 67.4 Coalitions establish **short-term and visible goals** to create momentum and ensure success of the coalition.
- 67.5 Coalitions develop strategies for **team building** among diverse stakeholders and decision-makers.





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# **APPENDICES**



## **APPENDIX A**

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# **SUMMARY OF TITLE X: THE RESIDENTIAL LEAD-BASED PAINT HAZARD REDUCTION ACT OF 1993 (P.L. 102-550)**



## **TITLE X: THE RESIDENTIAL LEAD-BASED PAINT HAZARD REDUCTION ACT OF 1993 (P.L. 102-550)**

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Title X is the most far reaching lead poisoning prevention legislation since the early 1970's. Because of its comprehensive nature, Title X has had enormous impact on the way housing, health, business and governmental agencies and individuals approach lead poisoning and its prevention. The statute has implications well beyond lead poisoned children and provides support to communities trying to implement primary prevention policies at the state and local level. This appendix offers a brief introduction to some of the major features of the statute. Interested readers are also referred to "Understanding Title X: A Practical Guide" available from the Alliance to End Childhood Lead Poisoning.

Title X establishes a framework for lead hazard reduction, both permanent removal (abatement of residential lead paint) and temporary (correcting defective paint and specialized cleaning to reduce dust lead levels). In addition the regulations ensure that a competent abatement industry is created within states to carry out lead hazard identification and reduction work. It also protects the workers in these industries and their families from lead poisoning caused by on-the-job exposure to lead dust and fumes. In states which fail to create a training and licensure mechanism for contractors and inspectors, Title X requires that the EPA enforce the regulations.

Title X has also stimulated the creation of lead-safe federally owned or subsidized housing. It requires that lead based paint in these housing units be brought into compliance with federal requirements to reduce lead hazards. All federally owned property, including housing owned by the Department of Defense, must meet the requirements of the statute.

Although housing or sanitation codes continue to be the province of state and local government, Title X ensures that people who live in privately owned housing are informed of the dangers associated with lead based paint. The property transfer and rental property notification requires that property owners inform potential buyers or renters of property built before 1978 of the possibility of lead based paint at the time of sale or rental. This will provide crucial information to families at a critical time.

Title X also has expanded the funds available for lead paint hazard reduction and control through grant and loan programs established by HUD, and by requiring that lead paint be explicitly considered by states before they qualify for community development funds such as Community Development Block Grants and HOME grants.

Title X has also established federal public education and information programs and integrated lead poisoning prevention education into other federal efforts such as those of the Consumer Product Safety Commission.

The law also resulted in the creation of a Task Force on Lead-Based Paint Hazard Reduction and Financing which includes members of key organizations and groups effected by lead paint.



## **APPENDIX B**

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## **GLOSSARY**



## GLOSSARY

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The following words or phrases relating to care for children and families affected by environmental lead hazards are defined or explained to assist the reader.

**Abatement:** The permanent covering or removal of residential lead paint hazards, which make them inaccessible to children and which conform to local or state statutes and regulations.

**Accessibility:** The degree to which health care is available to individuals; the absence of geographic, attitudinal, cultural, physical, architectural or financial barriers to care.

**Administrative Effectiveness:** Application of sound management techniques, including those pertaining to the mission, organizational structure, human resource development, information systems, policies, procedures and quality assurance systems in order to deliver care effectively and efficiently.

**Advocacy:** The process of speaking for, or on behalf of, an individual, group, or cause, especially when rights or interests are at risk.

**Alternative Housing:** Temporary housing provided to a family while their own home is undergoing lead hazard reduction or while the family seeks other permanent housing usually provided for six months or longer, also called *transitional housing*.

**Assessment (Individual):** The process of identifying the health status and health service needs of an individual child including: present developmental and functional levels, strengths and needs of both the child and family, conditions that may impede development and, where possible, the causes of preventable disability or disease.

**Assessment (Population):** The process of identifying the health care needs of a population through the regular and systematic collection, analysis and dissemination of data regarding the health status and problems of a community.

**Assurance:** The responsibility of public health agencies to encourage or require public or private sector entities to provide services necessary to achieve agreed upon health goals or to provide those services directly.

**Behavioral Issues Associated with Lead Exposure in Childhood:** Some research studies have reported associations between increased lead levels and behaviors such as distractibility, impulsivity, impersistence, inability to follow directions, daydreaming and low tolerance for frustration.

**Blood Lead Screening:** Direct measurement of lead in blood drawn from children who have no symptoms of disease. Screening tests are often, but not always, based on capillary blood drawn from a finger stick.

**Care Coordination/Case Management:** Services that promote the effective and efficient organization of and access to health services and resources to meet child and family needs. Care coordination or case management may include negotiating, facilitating or advocating for the delivery of services that are needed by an individual child and family. For the purposes of this document, the term *care coordination* is used instead of case management.

**Certified Abatement Contractor:** An individual who has completed the specialized training in lead hazard control and removal required under state or federal statutes. In some areas, contractors are also required to successfully pass an examination and to be licensed by a state agency before undertaking residential lead paint removal.

**Certified Inspector:** An individual who has completed specialized training in the identification of residential lead paint hazards as required by state or federal statutes. In some areas, inspectors are also required to complete an apprenticeship and successfully pass a qualifying examination in order to become licensed. Continuing education may be required to maintain licensure.

**Chelation:** A medical treatment that involves oral or injectable medications which remove lead from a child's blood and soft tissue and cause the lead to be excreted in urine or feces.

**City/State Consolidation Plan:** A planning document that cities and/or states use when applying for HUD funding. Under Title X of the Residential Lead-Based Paint Hazard Reduction Act of 1993 (P.L. 102-550), the consolidation plan must address residential lead paint hazards.

**Collaboration:** The establishment and maintenance of open, cooperative communication and working relationships among care-givers and the family in identifying goals and delivering care to individuals.

**Community:** An interacting population of various kinds of individuals in a common location. Families may define their communities in different ways depending on the type, intensity, and frequency of their needs and their culturally specific values. A community may exist at local, regional or national levels.

**Community-based Care:** Services delivered at a local level or as close to the child's home as possible; the major responsibility for planning, designing and implementing the services rests within the community as defined by the family.

**Comprehensive Assessment:** A broad assessment that is not limited to medical needs of the patient, but also addresses developmental, psychological and social functioning. The results of such an assessment serve as the basis for development of an individualized plan of care.

**Core Functions:** The primary responsibilities of public health agencies to identify health needs and populations at special risk, develop action plans to address these needs and assure that there is equal access to quality care. Core functions are frequently described as Needs Assessment, Planning and Quality Assurance.

**Cultural Competence:** Responsiveness to the values, beliefs, social norms, and behaviors of the individuals or population being served. Recognition of the variation in values of different population groups.

**Deleading:** The removal of lead paint from residential surfaces. This term is often used interchangeably with *abatement*.

**Developmental Assessment:** An assessment of a child's functional level and chronological age including physical, cognitive, psychosocial and communications development.

**Developmental Milestones:** Specific skills or behaviors that are keyed to specific chronological ages that can be used to assess whether a child is developing within normal expectations.

**Early Intervention:** A community-based program or set of services designed to be delivered early in a child's life in order to improve health outcomes for children who may be at risk for developmental delay. These programs may be funded partially through the federal legislation IDEA, Part C, which supports developmental services for children age birth to three years of age. Eligibility for these programs is defined by each state.

**Elevated Blood Lead Level:** In 1991, the threshold for elevated blood lead level was defined by the Centers for Disease Control and Prevention as a blood lead level of  $\mu\text{g}/\text{dL}$ . Levels as low as this may be associated with adverse effects. Children with mildly elevated blood levels should receive follow-up testing and family education services.

**Encapsulation:** A method of reducing lead hazards by covering them rather than removing them. Encapsulation materials are special coatings which make lead inaccessible. In some areas their use requires approval by state officials.

**Enforcement:** Carrying out of laws and regulations through the use of court process.

**Enhanced Care Coordination:** The extensive coordination of services that may be located both within and outside the health care sector needed to ensure that lead poisoned children and their families receive the maximum benefit from medical, educational, housing and legal interventions. *Enhanced care coordination* differs from *care coordination* in that its focus goes beyond the medical needs of the child.

**Entitlement:** A service or good which an individual has a right to receive because s/he belongs to a particular group.

**Erythrocyte Protoporphyrin (EP):** A molecule in blood which binds with iron to form hemoglobin. When lead levels are very high, lead interferes with this process and EP and iron do not bind well. As a result, children with lead poisoning also are often iron deficient or anemic. In the past EP was used to diagnose children with very high lead levels. This test has been replaced by the direct lead test as a screening tool.

**Family:** The basic unit of society having as its nucleus one or more persons consistently serving in the care-giving role for a child. This role may be filled by a parent, foster parent, guardian, brother or sister. In some cases, other members of the extended family such as an aunt, grandparent, or close friend may represent or substitute for the family.

**Family-centered:** Care that recognizes and respects the pivotal role of the family in the lives of children. The structure of services and policies that are designed to support families in their natural care-giving roles, promote normal patterns of living, and ensure family collaboration and choice in the provision of services to the individual child. Also includes family participation in program planning, policy development and evaluation.

**Family Supports:** A range of services that respond to specific needs as identified by family members. Such services may include transportation, housing abatement, transitional housing, legal services, parent-to-parent networks, babysitting/day care, advocacy services, and respite care.

**Free-standing Lead Center:** A community-based agency which provides medical and social services to lead poisoned children and their families. These services can include screening, case management, home visiting programs, referral, housing search and temporary shelter.

**Governance:** Authoritative direction or control of an organization.

**Hazard Reduction:** Specific measures taken to reduce the level of environmental lead contamination of house dust or soil including interim measures such as covering, cleaning with special agents, vacuuming using a HEPA filtration system and/or more permanent measures such as deleading of old painted surfaces.

**Health Care Delivery System:** The network of public and private health care professionals, services, and administrative structures that support and/or deliver in-patient ambulatory, and community-based care to meet the health needs of individuals or groups. The network includes tertiary care centers, health maintenance organizations, private specialty care providers, hospitals, publicly operated specialty care clinics, neighborhood health centers, primary care providers, home care and community health agencies and all payors of care.

**Health Care Professional:** A provider who meets the educational and/or licensure requirements to deliver certain health services. Health care professionals may have expertise in areas such as: audiology, child development, dentistry, education, genetics, counseling, medicine (primary and specialty care), nursing, nutrition, occupational therapy, orthotics, physical therapy, psychology, social work and speech and language therapy.

**Health Promotion:** The process of enhancing the development of positive health behaviors or outcomes for specific or general populations. Strategies may include health education and/or health care interventions.

**Hearing Acuity:** The ability not only to hear sounds of different volumes, but to distinguish spoken words.

**High Risk Community:** A geographic area, often a neighborhood or census tract, with a combination of old, poorly managed housing, large numbers of rental units and poverty. Children in high risk communities are more likely to become lead poisoned than in areas not similarly burdened.

**Home Visiting:** Assessment and treatment of a client, family and environment conducted in the home of the client, often by a professional nurse.

**Housing Code:** State or local statutes which regulate the condition of housing in a community. The housing code often sets minimum standards for wiring, heating and plumbing. It may also set standards regarding loose plaster and peeling paint and when enforced, can contribute substantially to a community's primary lead poisoning prevention efforts. In some areas these standards are called the *Sanitary Code*.

**Informed Choices:** The process by which parents/caretakers make decisions regarding medical treatment with as full an understanding of the risks and benefits of an intervention as is possible given the available information.

**Inspection:** The systematic identification of residential lead paint hazards within the house using x-ray fluorescence or one of the chemical tests available, in addition to testing of water, dust and soil. Inspections may be comprehensive and involve testing of most painted surfaces within the house, or they may be more streamlined and conducted only to determine whether any lead paint is detected. *Clearance inspections* are performed after hazards have been reduced to determine if a dwelling is safe for re-occupancy.

**In-patient Care:** Medical care which involves at least an overnight hospital stay.

**Interagency Cooperation:** A mechanism for sharing responsibilities between two or more agencies which may involve agreements, committees or shared detailing of staff. Interagency tasks are usually coordinated at the executive level in order to ensure their success.

**Lead Exposure:** The inhalation or ingestion of the chemical, lead, which has no physiological use in the body. Lead exposure is unavoidable in an industrialized society. In practice, this term has come to mean ingestion of lead at levels above those found in most individuals, but not high enough to be considered lead poisoned.

**Lead Free Housing:** Housing which has never been painted with lead paint or from which all lead paint has been removed. Houses built after 1978, the year when lead paint was made unavailable for residential use, are usually assumed to be lead free. Other housing should only be designated lead free by a licensed inspector.

**Lead Poisoning:** Diagnosis of a disease caused by the chronic ingestion of lead-based paint or other environmental lead hazards that results in a blood lead value above the threshold established by the Centers for Disease Control and Prevention. The threshold has undergone frequent revision. In 1991, the threshold was established as a confirmed severely elevated blood lead level of 20 µg/dL or higher, or persistent moderately elevated blood levels of 15-19 µg/dL at least three months apart.

**Lead-Safe Housing:** Housing in which there is no loose or peeling lead-based paint or plaster and which has undergone either temporary or permanent measures to reduce environmental lead levels. Housing is determined to be lead-safe if levels in dust, soil and on surfaces are tested and found to be below those established by state or federal statute and regulation.

**Lead Treatment Plan:** A written plan of services and therapeutic interventions, including medical, educational, housing inspection, abatement, home visiting and legal services, that is based on a comprehensive assessment of an individual child's developmental and health status and housing situation. This plan is designed and periodically updated by the lead treatment team.

**Lead Treatment Team:** An interdisciplinary group of professionals and family members who collaborate in planning, delivering and evaluating health care services for an individual child and family affected by lead exposure. The core members of the lead treatment team include a physician, nurse or nurse practitioner, community liaison and family members.

**Learning Disability:** A disability in processing information that may result in difficulty in academic performance in areas such as reading, writing or math.

**Legal Services:** A program which provides legal advice and representation for free or on a sliding scale to qualified individuals.

**Licensed contractors/workers:** Also called *licensed lead hazard reduction contractors*. Professionals who have completed specialized training to abate or reduce lead hazards in housing.

**Mandate:** A formal order given by a court or government official.

**mcg/dL ( $\mu\text{g}/\text{dL}$ ):** The abbreviation for microgram per deciliter, used as a measure of lead in blood. The level 10 mcg/dL or  $\mu\text{g}/\text{dL}$  is read, "10 micrograms of lead per deciliter of whole blood."

**Phlebotomy:** Drawing blood for diagnosis or transfusion.

**Policy Development:** The responsibility of public health agencies as defined by the Institute of Medicine, to take a leadership role in promoting the use of scientific knowledge in decision-making about public health and developing a strategic approach based on the positive appreciation of the democratic political process.

**Primary Care:** Health care for children that includes health maintenance, management of acute illnesses and some complications of chronic conditions, routine physical examinations and immunizations.

**Primary Prevention:** Activities which reduce residential lead hazards and prevent lead exposure before children are poisoned. Primary prevention efforts include widespread education and enforcement of housing codes undertaken on a broad scale, unrelated to the needs of an individual child.

**Public Awareness:** Increased consciousness and/or understanding within a community or broader society about the special needs of children affected by lead and their families.

**Quality Assurance:** A system of ensuring that health care services, facilities and agencies have the capability and resources necessary to deliver an acceptable level of services consistent with established beliefs regarding good practice. Strategies for quality assurance may include the setting of standards, monitoring, auditing, certification, program evaluation, training and technical assistance and reallocation of resources.

**Residential Lead Hazards:** Surfaces in a home which have deteriorated lead paint, or leaded plaster or lead paint which peels and mixes with house dust and soil.

**Resource Allocation:** The process of apportioning funds, staff, equipment, facilities, or anything of value to fulfill a specified objective.

**Secondary Prevention:** Activities which reduce residential lead hazards and prevent continued exposure for children who are already lead poisoned. Secondary prevention includes medical management and environmental investigation and remediation.

**Standards:** Pre-established objective criteria or benchmarks that define goals for performance in health care. Standards are derived from current knowledge, proven practice, laws and policies that identify the required components of care and are endorsed by both providers and recipients of care. Standards may be minimum compliance thresholds or may offer model targets for increasing quality and infusing the health care system with new practices. *Coordinating Care from Clinic to Community* is an example of a set of model, best practice standards.

**State Health Department:** The organizational unit at the state governmental level that has the responsibility to promote, provide and/or assure quality of health services for children and families.

**Statutes:** Laws enacted by state or federal legislative bodies.

**Surveillance:** Monitoring of children's blood lead levels and housing characteristics in order to be able to describe the nature and extent of lead poisoning or risks for lead poisoning in a geographic area and includes identifying changes in risk for a population.

**Tertiary Care:** The most specialized level of health care services characterized by highly trained specialists and access to sophisticated technologies.

**Tertiary Prevention:** Activities undertaken to limit the impact of lead poisoning on an individual child's development. These activities include not only lead hazard reduction but educational support and services which enhance a child's development.

**Toxicant:** A poisonous agent.

**Unsafe Renovation Practices:** Home repair techniques such as dry scraping of painted surfaces and the use of heat to soften paint before it is removed allow lead dust to escape and contaminate the house. These activities should be done only in carefully controlled conditions by trained personnel.

**WIC:** The Special Supplemental Nutrition Program for Women, Infants and Children, which provides iron rich food and nutrition education to families with children under five years of age and pregnant women who qualify.

**XRF or X-Ray Fluorescence:** Instrumentation used to determine the level of lead in paint.



## **APPENDIX C**

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# **ADDITIONAL NATIONAL RESOURCES**



## **ADDITIONAL NATIONAL RESOURCES**

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### **Alliance to End Childhood Lead Poisoning**

227 Massachusetts Avenue, NE  
Suite 200  
Washington, DC 20002  
202-543-1147

The Alliance has many publications available and provides technical assistance and advice to state, local and community-based agencies about primary prevention of lead poisoning, screening and follow-up for children with elevated blood levels. They are active in advocating for prevention legislation at the federal level.

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### **Columbus Apartment Association**

1225 Dublin Road  
Columbus, OH 43215  
614-488-2115

State legislation from the property owner's perspective; Ohio task force recommendations on essential maintenance practices.

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### **Conservation Law Foundation**

62 Summer Street  
Boston, MA 02110  
617-350-0990  
[www.clf.org](http://www.clf.org)

The CLF maintains a database of state lead laws and provides technical assistance to organizations (not individuals) interested in developing comprehensive lead poisoning prevention legislation.

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### **Consumer Products Safety Commission**

10 Causeway Street  
Room 224  
Boston, MA 02222  
800-638-CPSC

The CPSC provides testing of consumer items and information about products with dangerous levels of lead.

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**Environmental Information Association**

4915 Auburn Avenue  
Suite 303  
Bethesda, MD 20814  
301-961-4999

Trade association for lead hazard evaluation and control professionals, including inspectors, risk assessors, and abatement contractors.

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**Environmental Law Institute**

1616 P Street, NW  
Suite 200  
Washington, D.C. 20036  
202-939-3800  
[www.eli.org](http://www.eli.org)

Real estate law and legislation, environmental aspects of real estate transactions, indoor environmental health issues.

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**Medical University of South Carolina**

Pediatrics Department  
165 Ashley Avenue  
Charleston, SC 29425  
803-792-5345

Nationally known for expertise on childhood lead poisoning.

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**National Association of Realtors**

Attn: Government Affairs Department  
700 11th Street, NW  
Washington, D.C. 20001-4507  
202-383-1000  
[www.realtor.com](http://www.realtor.com)

Realtor, home seller, and home buyer perspectives on lead-based paint issues.

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**National Center for Lead-Safe Housing**  
10227 Wincopin Circle  
Suite 205  
Columbia, MD 21044  
800-624-4298

Technical standards and assistance to local lead poisoning prevention programs, affordable housing programs and the real estate, finance, and insurance industries.

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**National Lead Assessment and Abatement Council**  
PO Box 535  
Olney, MD 20830  
800-590-NLAC (6522)

Trade association for lead hazard evaluation and control professionals, including inspectors, risk assessors, and abatement contractors.

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**National Lead Information Center**  
8601 Georgia Avenue  
Suite 503  
Silver Spring, MD 20910  
800-424-5323 and 800-leadfyi (Prefer phone requests)  
[www.epa.gov/lead/nlic.htm](http://www.epa.gov/lead/nlic.htm)  
[nlic@optimuscorp.com](mailto:nlic@optimuscorp.com)

The National Lead Information Center operates a hotline providing general information to the public, a clearinghouse with a staffed phone line for more specific inquiries. It makes available HUD, CDC and EPA documents on lead poisoning, HUD listings of inspectors/risk assessors in a specific geographic area and lets the caller speak with information specialists. (Information available in both English and Spanish.)

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**National Multi-Housing Council/National Association of Apartments**  
1850 M Street NW  
Suite 540  
Washington, DC 20036  
202-659-3381  
[www.nmhc.org](http://www.nmhc.org)

National Association for multi-family housing providers, large apartment owners and managers.

**Parents Against Lead**

1438 E. 52nd Street  
Chicago, IL 60615-4122  
773-324-7824

PAL is a national organization of and for parents of lead poisoned children with chapters in several areas.

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**U.S. Centers for Disease Control and Prevention**

**Lead Poisoning Prevention Branch**

4770 Buford Highway, F 42  
Shamblee, GA 30341-3724  
1-888-leadlist (232-6789)  
[www.leadlist.org](http://www.leadlist.org)

Branch of U.S. government tracking lead poisoning prevalence rates and adverse health effects of lead poisoning. The CDC funds local and state activities in 44 states.

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**U.S. Department of Housing and Urban Development**

**Office of Lead Hazard Control**

451 7th Street SW  
Room B 133  
Washington, DC 20410  
202-755-1822  
[www.hud.gov/lea](http://www.hud.gov/lea)

Development and implementation of federal regulations and guidelines; grants to local communities for lead poisoning programs.

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**U.S. Environmental Protection Agency**

**Office of Pollution Prevention and Toxic Substances**

401 M Street SW  
Room 527/E. Tower  
Washington, D.C. 20460  
202-260-3810

Development and implementation of federal regulations and guidelines; overview of environmental impact of lead poisoning. Regional offices provide technical assistance and advice to individuals and groups as well as conducting work shops.

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Dedication Page, Pages 2, 10, 22, 34, 72



Rhode Island Tourism Division

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Thomas Landers, The Boston Globe

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