

ALPHA

American Lead Poisoning Help Association, Inc.

The Educational Needs of Children Exposed to Lead

For many of us, the discovery that our children were exposed to lead left us with a long list of unanswered questions. More often than not, we are left with this diagnosis sitting in our laps and little advice or guidance about what to do next. No matter who or where we are, the situation quickly becomes overwhelming.

Children exposed to lead have many needs including medical, nutritional, and therapeutic. However, one area that gets little attention is education. As long as children continue to be exposed to lead, it is essential for educators and families to understand their educational needs.

After years of dealing with therapists, specialists, educators and special educators, I have found that no one group has a clear understanding of these children's needs or how to address them. The statement "my child has lead poisoning" is typically met with surprise and confusion. People often react by asking if I meant that he had lead poisoning, as if this is something that must have happened to him but is now over. On the outside he looks like a healthy little boy, so it is hard for people to conceptualize that there is lead inside his body that continues to wreak havoc on his brain, nervous system, and organs. Unfortunately, his diagnosis was only the beginning of something he will have to live with for the rest of his life. With that in mind, let's start by saying that our children have lead exposure – their bodies have been invaded by a toxic substance that will continue to affect them for years to come.

What are the educational needs of a lead exposed child?

The educational needs of lead exposed children are generally not well understood; therefore, it is important to understand as much as we can about the affects of lead and the potential areas of concern in order to be able to line up appropriate services for these children.

What we do know is that lead is a neurotoxin* that affects the development of the brain and nervous system. The damage from lead is irreversible, and the half life of lead in the bloodstream and in bones can mean that most children will live with lead in their bodies for the rest of their lives. For example, many women exposed to lead during their childhood give birth to children who are exposed during gestation. This occurs because lead, deposited in the mother's bones during childhood, becomes mobilized during pregnancy and is absorbed by the developing fetus.

There are many variables that affect the prognosis of a child exposed to lead including: the age a child was exposed, to what degree that child was exposed, and the duration of the exposure. All lead exposed children have a high probability of developing cognitive, neuro-psychological, and neurobehavioral disorders, and face the potential to have developmental delays, learning disabilities, lowered IQ, mental retardation, behavioral problems, attention deficit, hyperactivity, autistic-like symptoms, Aspergers-like symptoms, sensory integration disorders, hearing loss, and auditory processing disorders.

Educational needs may differ from child to child; however, the one constant is that all of these children have an increased likelihood of developing some of the problems listed above. All children exposed to lead require some form of intervention to combat the damaging effects of lead.

How are educational needs addressed?

There are many systems in place to address the educational needs of children. These include the Individual with Disabilities Education Act (IDEA), Early Intervention, Section 504 of the 1973 Rehabilitation ACT, and Response to Intervention (RTI). On page two, you will find a glossary of terms with which you should become familiar as well as a list of related websites. Future articles will cover each topic in more detail.

Where do we go from here?

Until educators understand the specific needs of lead poisoned children, the responsibility falls on the parents and families of these children to educate the educators, therapists, and other professionals involved in their care. Lead exposure and poisoning is a chronic, degenerative illness. It is not uncommon to see a child with minimal symptoms at age three have more noticeable effects by the age of six, develop

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***Neurotoxin** – A poisonous substance that damages or destroys nerve tissue.

When the "lead" door opens, it becomes such an urgent issue that you feel you have to go full blast to try to make a change and help your community, or try to learn and make some sense out of what is happening to your family. KF

Alexandra Larson is the mother of 4 lead poisoned daughters. Her and her husband moved to Cleveland in 1998 from San Diego so her husband could attend graduate school. Like so many young families they bought their first home in quaint, suburban location, drawn because of the character of the older homes. The house they purchased was supposed to be for "only a few years". They had hoped to make some repairs and remodel and then sell the house.

Alexandra's daughter "Alexi" had been suffering from asthma and pneumonia starting at age 1 and was spending 9 days of every month for nearly 10 months at Fairview hospital. It suggested she enter a local asthma study being conducted in 2001. Prior to beginning the study Alexi went through a series of routine blood tests, one of which was lead. Her mother received a life changing phone call the next morning that she needed to take Alexi to Fairview Hospital immediately to start a multi-day long therapy know as Chelation to remove the high blood lead levels. It required her parents to stay with her 24/7 while she underwent several rounds of IV medication known as EDTA followed by several weeks on an oral Chelation medication called Chemet. Alexi underwent this procedure twice in 1 year as her lead levels shot back up 9 month after the first treatment.

At the time Alexi had the highest Lead level in Cuyahoga County in 10 years. The poisoning wasn't caused by Alexi eating paint chips. It was caused by inhaling microscopic Lead dust particles that were sloughing off the tracks of the dining room windows which her mother opened and closed frequently. The poisoning manifested as Asthma for 10 months.

Alexandra's life now consists of visits to Alexi's Neurologist at the Cleveland Clinic, weekly meetings with Alexi's Special Education teachers at Emerson Elementary and her career as a Pharmacy Technician which took root out of the necessity in needing to learn about all of the medications Alexi takes regularly. Alexi cannot fully attend regular classes as the Lead caused major neurological damage in her short term memory and her ability to comprehend new information. Every day is a struggle, but every step forward is a victory. Alexandra hopes that by speaking up and raising awareness of what Lead poisoning did to her child that she can help prevent another child from going through it. Whether the paint is on new, imported toys or in a home built before 1970 it is still a hazard to young and old alike. She wants people to know that it is not a problem of the past.

Lead and Education Terms Parents Need to Know

Individuals with Disabilities Education ACT (IDEA): A federal law that ensures services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to eligible infants, toddlers, children and youth with disabilities.

IDEA Part B: The section on Special Education and related services that pertains to children and youth (ages 3-21)

IDEA Part C: The section on Early Intervention Services that pertains to Infants and toddlers with disabilities (birth-2) and their families.

Early Intervention (EI): Early intervention applies to children of school age or younger who are discovered to have or be at risk of developing a handicapping condition or other special need that may affect their development. More information can be found under **IDEA Part C**.

Section 504 of the 1973 Rehabilitation Act: A civil rights law designed to eliminate discrimination on the basis of disability in any program or activity receiving Federal financial assistance. Section 504 guarantees certain rights to individuals with disabilities, including the right to full participation and access to a *free and appropriate public education (FAPE)* to all children regardless of the nature or severity of the disability.

Individual Family Services Plan (IFSP): According to IDEA 2004, IFSP must be implemented for all children with developmental delays by their third birthdays.

Individualized Education Plan (IEP): A written plan that describes the educational program designed to meet a child's unique needs. Each child who receives special education and related services must have an IEP. An IEP is a legally binding document.

No Child Left Behind Act (NCLB): NCLB requires schools to bring all students to a proficient level in reading, math and science by 2014. School districts and states must provide detailed report cards to the public about their progress toward this goal. NCLB includes requirements about parental involvement, highly-qualified teachers, scientifically based reading instruction, tutoring and supplemental educational services, research-based teaching methods, and school and school district report cards.

Least Restrictive Environment (LRE): Also known as the Inclusion Principle, LRE means students with disabilities should have the opportunity to be educated with their non-disabled peers, to the greatest extent possible; have access to the general education curriculum, extracurricular activities, or any other program that non-disabled peers would be able to access. Because students' need and interests vary, there is no single definition of what an LRE will be for all students.

Response to Intervention (RTI): A tiered process that can be used to determine if and how students respond to specific changes in instruction. Student's needs are first addressed within the classroom. Evaluations of the student's progress are ongoing and if classroom interventions do not work, functional and multidisciplinary assessments may be performed and additional educational interventions may be implemented.



Important Tip – keep copies of all evaluations, medical records, test results, and reports. These are your records and you are entitled to copies. It is helpful to create a binder to keep this information to bring with you to doctor visits, meetings with diagnosticians, therapists, and school personnel.

Does anyone think that the leg pains are "growing pains" but in the sense that as they grow, lead is re-mobilizing into the blood stream? LK

Around ALPHA

Since the Spring newsletter, ALPHA has been in demand! ALPHA had several parents attend the Charleston, SC April conference, including: Barbara Miller (ID), Shannell Wimbush (NJ), Angela Ausborn (IA), Michele Gaffney (TX), Sharon Lara (SC), Marian Johnson (NJ), Kim Fuelling, Kristin and Michael Joyner (NC). Congratulations to Michele and Kim on receiving Lead Star Awards!

On May 14, 2008 the Rhode Island Childhood Lead Action Project held a Press Conference in Providence, Rhode Island, before the appeal to the RI Supreme Court. Unfortunately, the court sided with the lead industry in its early July decision. Great teamwork by CLAP and other advocacy groups in the classic David and Goliath story, only Goliath won and the children lost.

May 22, ALPHA was in Hartford, Connecticut, participating in the 2008 Health Education Lead Poisoning Community and Parent Informational Forum, a fantastic effort headed up by Dr. Vivian Cross. The following week, ALPHA presented at the National Nursing Center Consortium Lead Safe Babies Training in Philadelphia, Pennsylvania, and one week later, the Ohio Healthy Homes Conference in Columbus, Ohio. Over 71 Wipe Out Lead New Jersey dust testing kits were distributed by ALPHA last quarter.

This is the 1st school year that the state of Iowa will be requiring lead testing before children begin school...



Banner displayed at Press Conference May 14, 2008 in Providence, Rhode Island, indicating the 614 RI children lead poisoned in 2007

Iowa's Katrina

After Iowa's bad winter where the state had its record snow fall, we were all hoping for spring to come. Little did we know what spring would bring? Severe tornados and flooding hit Iowa in June causing 84 of the states 99 counties to be listed as disasters.

Iowa's 2nd largest city, and one of the oldest cities, Cedar Rapids, was hit the worst. A levee was compromised in downtown Cedar Rapids. 1,300 city blocks were under water forcing the evacuation of nearly 24,000 people to leave 4,000 homes. Quite a few of these homes had up to 8 feet of water.

Since Iowa is ranked #5 of homes built before 1950, this also causes serious lead hazards.

TV commercials are not addressing lead specifically but are reminding people to use licensed contractors to work on their homes. As well as many sites and news sources reminding people to not go near the flood waters due to the many hazards and to not let children near any affected areas during clean up. FEMA and the Red Cross have been handing out supplies to help people clean up from the waters. Such as bleach, masks, and gloves.

Estimates put the property damage at \$765 million. Initial estimates indicate that it will take the state roughly 6-7 years to recover from this devastation.

www.ALPHALead.org

<http://health.groups.yahoo.com/group/ALPHALEAD>

<http://groups.myspace.com/ALPHALEAD>

NEW!!! www.facebook.com/group.php?gid=29788759920

Ladies, there is no "handbook" on treating lead, we are writing it as we go. That is why we need to keep this dialogue open, take notes on what works and what doesn't. ST

FREE DUST TESTING

ALPHA has FREE lead dust kits to test houses in **New Jersey** at this time. Families can test one window and one floor sample, and also receive a free \$5 gift certificate for Shop Rite or Pathmark.

Funding is available to remove lead hazards throughout New Jersey. Contact Leann at 609-332-6730.



Riverside Elementary Environmental Club and Student Government had 13 kits returned in 6 weeks! Special thank you to the Riverside Boost Café and Boost Factory for providing additional incentives!

The ALPHA Files Newsletter is published quarterly and is intended for families learning about or dealing with lead in their children. Please copy and distribute within your communities.

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Email comments or suggestions to:
Info@ALPHALead.org

Next newsletter: September 2008

So consider yourself a member of ALPHA with the responsibility to spread the idea that lead poisoning is a threat to society and children. MM

Upcoming Conferences:

*Lead & Healthy Homes Conference 8/26/08
Cedar Rapids, IA Contact Ann @ (319) 892-6000*

*2008 Healthy Homes Conference 9/15-17/08 -
Baltimore, MD
www.hud.gov/offices/lead/2008NHHC.cfm
**toy testing will be available at ALPHA table*

*2008 Indiana Lead Safe and Healthy Homes
conference 11/5-6/08—Indianapolis, IN
mccabe@ikecoalition.org*

*National Indoor Environmental Health & Technologies
Conference April 28-May 1, 2009—Orlando, FL
www.leadmoldconferences.com*

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You are not alone anymore...

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THIS NEWSLETTER IS ALSO AVAILABLE ON-LINE AT:
[HTTP://ALPHALEAD.ORG/SUMMER_2008_V4I2.PDF](http://ALPHALEAD.ORG/SUMMER_2008_V4I2.PDF)

Educational Needs *continued from page 1*

additional problems by the age of twelve, and have severe delays by the time they are eighteen.

I've often found that people fail to see the need to address problems they can not see; if they cannot quantify the problem then, essentially, it does not exist. It can be difficult to get educators and other professionals to believe that even if a child is meeting their milestones at one stage of development, monitoring and maintenance may be necessary to prevent regression or ward off delays and problems that may develop as the child develops.

In my opinion, because it is well known that the presence of lead in a developing body is likely to cause problems, preventative measures *should* be taken to help these children combat the detrimental effects of lead and reach their greatest potential.—*Michele Gaffney*

Authors note: *The intention of this article is to provide an overview of the guidelines that apply to the educational needs of a child who has been exposed to lead. Each individual is unique and has different needs depending on a variety of factors. The information provided in this article is intended to help you understand the educational component of dealing with a lead exposed child. Please consult the professionals who are working with your children to learn more about how to address the needs of your child. For questions or comments about this article, please write to michele@alphalead.org.*

Useful Websites:

<http://idea.ed.gov/> - The US Department of Education site on IDEA.

<http://www.ed.gov/nclb/landing.jhtml> - The US Department of Education site on the No Child Left Behind Act.

<http://www.ed.gov/about/offices/list/ocr/qa-disability.html> - The US Department of Education Office for Civil Rights site pertaining to Section 504 and Title II.

www.wrightslaw.com – This site provides information about special education law, education law, and advocacy for children with disabilities. It includes thousands of articles, cases, and resources about a variety of topics.

http://en.wikipedia.org/wiki/Main_Page - Wikipedia is a free encyclopedia that is edited by the public.



Charleston, SC April 1-4, from top left, clockwise: Kim Fuelling, Angela Ausborn, Shannell Wimbush, Barbara Miller, Marian Johnson, Leann Howell and Michele Gaffney.

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