THE COLLABORATIVE ON HEALTH AND THE ENVIRONMENT

# LEARNING AND DEVELOPMENTAL DISABILITIES INITIATIVE REGIONAL MEETING

## YAI/National Institute for People with Disabilities

### 460 WEST 34TH STREET - NEW YORK CITY

**Thursday, June 9, 2005**

# NOTES

## Overarching Goals:

- Enhance understanding of existing and emerging science linking certain chemical exposures to learning, behavioral and developmental disabilities.
- Highlight current initiatives and encourage broader education of key stakeholder groups.
- Foster effective collaborative educational and policy initiatives on a regional level between researchers, health care professionals, health-affected groups and environmental health and justice advocates in order to reduce environmental pollution that can undermine children's healthy development.

## Brief Synopsis of Meeting:

Over 80 people attended the Learning and Developmental Disabilities Initiative (LDDI) regional meeting in New York City on June 9, 2005. Researchers, health care professionals, health-affected organizations, government agency representatives, environmental health and justice groups, self-advocates and philanthropists participated. This day-long workshop highlighted the state of the science on how environmental contaminants may adversely impact brain development as well as educational and policy initiatives aimed to address these concerns.

The remarkable caliber of both the speakers and participants made for a lively day of discussions, presentations and interactions. During the final session of the day, participants remained energetically engaged—offering ideas and suggestions for next steps. These notes include a summary of presentations and ideas for future collaborative efforts in New York State.

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## Summary of Presentations:

### Overview of the Learning and Developmental Disabilities Initiative

- Elise Miller, MEd, *Executive Director, Institute for Children's Environmental Health*

According to recent studies, the incidence of learning and developmental disabilities appears to be rising, affecting about one in six children in the U.S. under the age of 18. Emerging science suggests that exposures to certain neurotoxicants such as lead, mercury, pesticides, polychlorinated biphenyls (PCBs), brominated flame retardants, solvents and other known and suspected neurotoxicants can contribute to neurological problems including learning and developmental disabilities (LDDs). Recent research also shows that the developing fetus and children are particularly vulnerable to environmental exposures. Given this, protecting children from exposures to neurotoxicants starting as early as fetal development is an essential public health measure if we are to help prevent further increases in LDDs.

The Learning and Developmental Disabilities Initiative (LDDI) was established in 2002 as a working group of the Collaborative on Health and the Environment. The primary mission of LDDI is to foster collaboration among learning and developmental disability organizations, researchers, health professionals and environmental health groups to address concerns about the impact environmental pollutants may have on healthy brain development. LDDI currently has over 160 organizational and individual members engaged in educational and policy efforts.

Since its inception, LDDI has undertaken a number of activities, including: 1) organizing a major national meeting at the National Institutes of Health and several regional meetings; 2) working with member groups to launch major environmental health initiatives for LDD constituencies; 3) presenting at various meetings around the country; 4) co-sponsoring a Congressional briefing; 5) publishing Practice Prevention columns and other materials which translate emerging science for lay audiences; and 6) supporting members' efforts to leverage specific legislation and regulations nationally and on the state level.

### Keynote – Overview of the Science Linking Environmental Pollutants and Learning and Developmental Disabilities

- Ted Schettler, MD, MPH, *Science Director, Science and Environmental Health Network*

Fetal, infant and child brain development is guided by complex interactions among genetic, environmental and social factors. Nutritional deficiencies, toxic chemicals, radiation and infectious agents can have significant and long lasting impacts on the developing brain. The effects of lead, alcohol and tobacco smoke on the fetal or infant brain are well known and widely studied. More recent information addressing the impacts of mercury, PCBs, and some pesticides has become available in the last 10-15 years. However, the impacts of many industrial chemicals to which the general population is widely exposed are unstudied and unknown.

This presentation will describe the evolution of our understanding of the neurodevelopmental impacts of these more commonly examined compounds. It will include examples of substances for which there is cause for concern but where important data gaps remain. It will include examples of interactions among genetic, nutritional, and chemical agents that impact exposure levels or outcomes. Finally, it will describe various levels of possible policy responses to the known and emerging science. Responses from the perspective of clinical medicine, public health, or ecological systems may differ significantly, suggesting that ethical considerations should be prominently featured in any public discussion surrounding these important issues.

**Morning Plenary - Specific Areas of Scientific Research on Neurotoxicants**

- Moderator: Leo Trasande, MD, MPP, *Assistant Director, Center for Children's Health and the Environment Instructor, Departments of Pediatrics and Community and Preventive Medicine, Mt. Sinai School of Medicine*

Presentations:

1) Virginia Rauh, ScD, *Professor of Public Health and Deputy Director of the Columbia Center for Children's Environmental Health, Mailman School of Public Health, Columbia University*

The Columbia Center for Children's Environmental Health is evaluating effects of environmental exposures during pregnancy on fetal growth and infant neurocognitive development in a cohort of African American and Dominican mothers and infants in New York City. Exposures include polycyclic aromatic hydrocarbons (PAH), environmental tobacco smoke (ETS), and pesticides. A battery of data collection strategies includes personal air monitoring of the mother during pregnancy, detailed questionnaires and laboratory analyses of biomarkers in blood samples collected from the mothers and newborns at delivery. To date, over 600 pregnant nonsmoking women have been enrolled and their infants are being followed prospectively through school age.

Key results include the findings that high prenatal exposure to PAH as estimated by personal air monitoring of the mother was associated with lower birth weight ($p = 0.003$) and smaller head circumference ($p \leq 0.01$) among African American newborns. Among both African Americans and Dominicans, ETS was associated with decreased head circumference at birth ($p=0.04$); and there was a significant interaction between prenatal exposure to ETS and PAH-DNA adducts in cord blood such that the combined exposure to high ETS and high adducts had a significant multiplicative effect on birth weight ($p=0.04$) and head circumference ($p=0.01$). ETS exposure and material hardship during pregnancy were significantly inversely associated with infant cognitive development measured at two years ($p<0.05$), and there was an interaction effect such that infants with both exposures had a 7-point decrement in cognitive scores at 24 months of age. Compared to non-exposed children, those with prenatal ETS exposure were twice as likely to be classified as significantly delayed.

Finally, levels of the insecticide chlorpyrifos in umbilical cord blood samples were inversely associated with birth weight and length ($p<0.05$). Combined measures of the insecticides chlorpyrifos and diazinon (adjusted for relative potency) were also inversely associated with birth weight and length ($p \leq 0.03$). The associations between birth weight/length and chlorpyrifos

and diazinon were highly significant ($p \leq 0.007$) among newborns born prior to the 2000-01 U.S. Environmental Protection Agency's regulatory actions to phase out residential use of these insecticides, but not among newborns born after 1/1/01 ($p > 0.8$). These results indicate that interactions between toxicants as well as between toxicants and socioeconomic stressors during pregnancy impair fetal growth and/or child cognitive development in this minority cohort. They support recent regulatory action to phase out residential uses of chlorpyrifos and diazinon and indicate the need for further preventive measures to reduce ETS and PAH exposures.

2) David Carpenter, MD, *Professor and Director, Department of Environmental Health & Toxicology, School of Public Health, University of Albany*

Polychlorinated biphenyls (PCBs) are industrial chemicals that had many useful purposes. Their manufacture and use in the US was stopped in the late 1970s because they were found to persist in both the environment and in the human body. Everyone has some PCBs in their bodies, which we get from primarily from food. PCBs are fat-soluble substances and are present in fish from contaminated waters as well as lower levels in almost all animal fats, milk and eggs. It takes about 10 years for the human body to rid itself of half of the PCBs that come from these exposures, and as a result the levels in people increase with age.

PCBs cause a variety of adverse health effects, including cancer, suppression of the immune system and alteration of sex hormones. However one of the most serious of the harmful effects of PCBs is that they cause a lowering of IQ and changes in behavior of children who are exposed before birth to the PCBs in their mother's body. Children that were born to mothers who unintentionally ate PCB-contaminated cooling oil or large numbers of PCB contaminated fish show reductions of IQ of about 5-7 points, which is similar to the effects of exposure to lead and methyl mercury. These children tend to have a shortened attention span and hyperactivity, with a reduced ability to deal with frustration. There is some evidence that these effects are irreversible. Infants are also exposed through breast milk, although the benefits of breast feeding probably outweigh the hazards. Recent studies have also reported memory problems in adults exposed to high levels of PCBs. It is urgent that we get PCBs and other such contaminants out of our food supply, and to provide information to consumers that will help them reduce their exposure.

3) Mady Hornig, MD, *Associate Professor of Epidemiology and Director of Translational Research, Center of Immunopathogenesis and Infectious Diseases, Mailman School of Public Health, Columbia University*

Autism is one of the most highly heritable neuropsychiatric disorders, yet its genetics remains elusive. Reports of a more than ten-fold increase in the prevalence of the disorder over the past few decades are suggestive of potential risk factors from the environment. Infections, toxins, or dietary antigens, or common host responses to these risk factors, may act as triggers or amplifying factors in autism pathogenesis. We propose a "three strikes" hypothesis, wherein environmental factors (first dimension) interact with susceptibility genes (second dimension) during vulnerable periods of brain development (third dimension of timing) to produce damage and dysfunction. This presentation will review data from animal models and epidemiologic

studies that shed light on pathways leading to autism-like CNS neurodevelopmental damage after exposures to environmental contaminants such as mercury. Gaps in the existing literature on mercury and neurodevelopmental disorders such as autism will be identified, ongoing projects described, and ways in which knowledge derived from such studies may be translated into novel strategies for intervention and prevention will be outlined.

## Afternoon Plenary:
## From Science to Education and Advocacy: Model Initiatives in New York State

- Moderator: Claire Barnett, MBA, *Executive Director, Healthy Schools Network*

Presentations:

1) Sheryl White-Scott, MD, *Director, St. Charles Developmental Disabilities Program, St. Vincent Catholic Medical Cente*r

   Individuals with developmental disabilities (DD) face ongoing challenges throughout their lives. Improvements in health care services and technology have helped children with DD live into adulthood. The impact of environmental exposures on adults with DD is unknown. We do know that individuals with DD are now living into their late 60's. The lifespan for the general population is late 70's. There are several barriers to health care for adults with DD including lack of access, lack of or limitations of health insurance and lack of knowledgeable providers. Do environmental toxins play a role in the health disparities that occur in adults with DD? Do environmental toxins cause additional cognitive impairments? The Wingspread Conference in 2003, "Pollution, Toxic Chemicals and Mental Retardation," began a dialogue between the environmental health community and the DD community to explore these issues. There were many recommendations from this conference addressing policy, research and clinical needs in environmental health. The American Association on Mental Retardation's (AAMR's) Environmental Health Initiative is one of the outcomes from the conference. This initiative has already implemented many of the recommendations from the Wingspread Conference to address educating individuals with DD, family members, health professionals, policy makers and legislators about environmental issues. There are also plans to address the lack of clinical and research information with regards to environmental issues and DD. Increasing awareness and knowledge about environmental toxicants & DD is a major factor in improving the quality of life for individuals with DD.

2) Peggy Shepard, *Executive Director, West Harlem Environmental Action (WE ACT)*

   Since 1998, the Columbia Center for Children's Environmental Health (CCCEH) in collaboration with WE ACT For Environmental Justice has conducted a cohort study of mothers and children in Northern Manhattan and the South Bronx in New York City. The Center has enrolled a cohort of 700 mothers and children of color who belong to one of the most at-risk urban populations in this country with respect to environmental exposures, social adversity, and childhood health problems. Community concerns about exposures related to poor-quality housing have provided a major impetus to address housing-related problems in collaboration with the NYC Housing Authority.

Findings include: Prenatal exposure adversely affects birth weight and head circumference among African-American infants. Prenatal exposure to multiple urban pollutants is common and levels are highly variable. Personal air samples and/or biomarkers indicated that 100 percent of the cohort had prenatal exposure to (polycyclic aromatic hydrocarbons (PAHs) and pesticides with levels varying over two to four orders of magnitude; 43% had prenatal ETS exposure. Prenatal PAH exposure adversely affects birth weight and head circumference among African-American infants. The cohort has high rates of respiratory symptoms which are requiring considerable health care.

The partnership with CCCEH represents a critical alliance towards improving housing-related health. WE ACT's role is to translate and disseminate the research of the Center to the broader community and to coordinate policy outcomes. The home environment accounts for a major share of our exposure to toxics, allergens and gases that can cause disease and harm health. WE ACT's Health Homes project approaches this crisis with a holistic approach to housing and health that mobilizes community health workers, housing inspectors, policy makers and health departments to take a broader look at this interrelationship of housing and health to develop new policies that reduce environment exposures in housing.

The project seeks to: a) educate untraditional allies in the housing arena on sources, health effects, the regulatory context of pests and pesticides; and b) discuss and lay the foundation for taking action on a broad policy level.

3) Heather Loukmas, *Executive Director, Learning Disabilities Association of New York State*

The Learning Disabilities Association of America (LDA) is the largest organization advocating for and providing services to individuals with learning disabilities and their families. LDA is a three-tiered organization with national, state and local presence. In New York State, there are 7 regionally based LDAs that provide a variety of services to individuals with learning disabilities and their families. Ms. Loukmas shared statistics on the prevalence of learning disabilities in the United States and New York State. Statistics indicating the growth in learning and other developmental disabilities over the past 30 plus years and actual dollar costs of environmental toxins such as lead and mercury were also shown. Ms. Loukmas then went on to describe some of the specific activities the LDA has engaged in to raise awareness on the link between exposure to environmental toxins and learning disabilities. LDA has created a campaign known as the Healthy Children Project to raise awareness and bring about change in policies impacting children’s environmental health. The project involves action at the national, state and local level. Some of the specific issues LDA of New York State has been working on include a bill to ban Lindane for treatment of lice, in-state regulations to reduce mercury pollution, working collaboratively to establish a statewide Alliance for a Toxic Free Future and more. LDA of Western New York in Buffalo and LDA in Rochester, NY have been working on reducing lead poisoning in their local communities as well.

*4)* Kathy Curtis, *Executive Director, Citizens' Environmental Coalition (NY)*

Citizens' Environmental Coalition (CEC) is New York's premiere state-level environmental health advocacy organization, having worked to solve and prevent pollution problems in NYS since 1983 with a mission to eliminate pollution from homes, schools, and workplaces through legislative advocacy, grassroots organizing, and public education.

Ms. Curtis shared recent innovations in New York environmental health policy, and current efforts underway to improve upon them. These policies fall into two categories: "Stick" initiatives, such as a bill that greatly reduces the use of thimerosal in vaccines, phases out mercury in consumer products, and eliminates the use of Lindane (hexachlorocyclohexane) on humans for treating lice. "Carrot" initiatives include a Safe and Sustainable Procurement Act, which promotes safer products by encouraging state agencies to implement safe and sustainable procurement practices, and the Small Business Pollution Prevention policy, which will and provide on-site technical assistance to reduce the use of toxic chemicals by small businesses.

CEC coordinates New York's burgeoning Alliance for a Toxic-Free Future, with over forty Health, Labor, Community, State-level, Environmental Health and Justice participating groups. By preventing pollution at its source, we envision a future where children are born without toxic chemicals in their bodies, and are not at any point in their development exposed to them through the food they eat, the air they breathe, the water they drink, or the dirt in which they play. This is the goal we share in common with the Learning and Developmental Disabilities Initiative.

5) Steve Boese, MSW, *New York State Director, Healthy Schools Network*

Children are uniquely vulnerable to environmental toxins and schools are unique environments worthy of intensive attention in order to protect children from environmental exposures. Schools are on average old, poorly maintained and in poor overall condition. Schools are also typically the most densely occupied public structure. Yet despite these factors, schools are largely unregulated workplaces for children. There is no reporting of environmental illness or exposures. Similarly, there is no public authority; not most health departments, not OSHA, not even most building code enforcement agencies; that have the authority to protect children from school environmental exposures.

The LDDI Conference intends to bridge state of the art science regarding children and the environment with public policy advocacy. The Healthy Schools Network knows that State policy makers are inundated with issues and bills that demand their attention, and their votes, on a very wide variety of topics. Translating sometimes difficult to summarize scientific information for use by harried policy makers can be a daunting process. Scientists are comfortable with uncertainty, probabilities, and information that may suggest harm from toxins, but doesn't necessarily prove that harm. The challenge for LDDI is in translating these complex and important messages in a manner that will be understandable, usable and productive for policy makers.

The Healthy Schools Network has been successful with legislation that protects children from CCA in playground equipment, elemental mercury in schools, healthy and high performance school design and other initiatives. Most recently we have been instrumental in moving an agenda to bring "green" cleaning products and practices to New York Schools. Our success is based in part on communicating a message to policy makers that not only makes clear the current harm, but also makes clear an alternative that is not only feasible, but desirable. For example, our message that toxic cleaning products are harmful to children, but green cleaning is healthier, effective and saves money for schools.

The LDDI message is a critically important one. Articulating this message in a manner that persuasively penetrates the dense agenda of the influential policy maker is a key to success.

## Plenary Discussion:
## How Do We Move Forward Collectively on These Issues?

Co-moderators: Elise Miller, MEd and Patti Wood, *Executive Director, Grassroots Environmental Education*

**Specific suggestions:**

- Form an Environmental Health Caucus both at the legislative level in New York State and also as a collaborative structure for further work together (on the national level, Dr. George Lambert has just catalyzed a Children's Environmental Health Caucus with support from Representatives Holt and Saxton, both from New Jersey).
- Educate different audiences about children's environmental health with materials targeted to that audience, such as policymakers, pediatricians, midwives, parents, teachers, OB/GYNs, etc.
- Hold candidates, policymakers and health care providers accountable to protecting public health, particularly for those with learning and developmental disabilities/self-advocates.
- Tap into other initiatives such as the New York City Mayor's efforts on global climate change and show how that's relevant to environmental health.
- Collect model local bills so that other communities don't have to reinvent the wheel.
- Offer cross-training between constituencies on each other's issues to help facilitate collaboration, particularly when there are language barriers between different groups such as with the brownfields initiative.
- Ensure health-affected and environmental justice groups are included in discussions and research on environmental health from the start.
- Outreach to underserved communities more effectively by providing transportation, child care, etc. which would make community members more able to participate in meetings and educational workshops.
- Press for more community-based research.
- Draw from successful programs and initiatives on the local level.
- Develop media strategies that include a cross-section of constituencies, such as scientists talking about policy implications.
- Write regular articles on environmental health for local newspapers; even submit once a week collectively.

- Make messages positive and solution-oriented so that people come away feeling empowered.
- Use quantitative data and references along with personal stories.
- Highlight economic impact of exposures to toxics and reward progressive corporations for producing and marketing less toxic alternatives.
- Raise children's environmental health issues at the annual lead poisoning conference to be held in October.
- Ensure all relevant information is included in outreach materials—for example, in regards to mercury, include not only power plant emissions, fish consumption, dental amalgams and vaccines, but also ritual use of mercury.

**Next steps:**

- Heather Loukmas, director of the Learning Disabilities Association of New York State, has agreed to take the lead in developing a LDDI collaborative in New York. She will help to coordinate interested groups and follow-up on some of the suggestions above in order to translate the science into stronger public policy. Elise will work with Heather to take these steps.
- Rob Fletcher, director of the National Association for the Dually Diagnosed (NAAD), expressed interest in having Ted Schettler and Elise Miller speak at the next annual meeting of NADD. This would be the first time NADD would have a session on environmental health.