LEARNING AND DEVELOPMENTAL DISABILITIES INITIATIVE

MEETING NOTES

National Institutes of Health
Bethesda, Maryland
May 19, 2004

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Sponsored by:
The John Merk Fund
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(Notes: Acronyms and abbreviations are listed in the Appendix. Many of the slides from PowerPoint presentations are available online at http://www.iceh.org/Pages/LDDI.html.)

The Learning and Developmental Disabilities Initiative (LDDI), a national working group of the Collaborative on Health and the Environment (CHE), held its first major national conference in the Natcher Conference Center at the National Institutes of Health in Bethesda, Maryland, on May 19, 2004. Almost 80 researchers, health care professionals, government agency representatives, philanthropists, learning and developmental disabilities advocates, and environmental health and justice leaders attended.

The overarching goals for the meeting:

- Enhance understanding among learning and developmental disability (LDD) groups and key environmental health organizations about research linking certain environmental pollutants to learning and developmental disabilities (LDDs);
- Encourage further support for scientific research on these linkages;
- Highlight existing initiatives of LDD groups that are already educating their constituencies about how to be more effective in protecting children and future generations from exposures to neurotoxicants;
- Foster greater collaboration between researchers, health care professionals, LDD groups, environmental health and justice advocacy organizations and others concerned with environmental contributors to neurological development;
- Define specific educational and policy opportunities regarding environmental contributors to LDDs; and
- Engage a "critical mass" of those in the LDD sector and other interested organizations to help move these opportunities forward.

Frank Hatch, chair of the Board of Directors of the John Merck Fund, welcomed participants and underscored the importance of LDDI as a "catalyst for change." Through this initiative, he noted, the LDD sector can work more effectively together with scientists and other advocates to prevent exposures that can undermine children's healthy brain development.

He then introduced Elise Miller, MEd, executive director of the Institute for Children's Environmental Health, national coordinator for LDDI and conference organizer. She extended her deep appreciation to Frank Hatch, Ruth Hennig and others at the John Merck Fund for their support of this conference and for their vision and leadership in developing LDDI. She then provided additional information on the formation and mission of LDDI as part of CHE, outlined the conference goals and introduced the keynote speaker, Lynn Goldman, MD, MPH, MS, professor at Johns Hopkins University, Bloomberg School of Public Health.

Keynote

Lynn Goldman, MD, MPH, MS –Translating the Science on Neurotoxicants into Effective Policy

Dr. Goldman began by describing how developmental disabilities are among the most important children's health problems in the United States (US) and how prevention of environmental pollutants is one key to addressing these disabilities. While a number of persistent pollutants – lead, polychlorinated biphenyls (PCBs) and dioxins, and methylmercury – have been linked with developmental neurotoxicity in children, she noted we do not yet completely understand the role of these and other environmental exposures in developmental disabilities. Important environmental policies include testing chemicals and pesticides, expanding funding for tracking developmental disabilities, and controlling persistent pollutants, but she added that most of these do not go far enough. Dr. Goldman then presented a summary of neurotoxicity testing, including progress to date, controversies and recommendations. She summarized problems and actions regarding reducing exposures to flame retardants, perfluorinated chemicals, lead and mercury. She concluded with specific policy and action recommendations: 1) The US needs to ratify and support the Global Persistent Organic Pollutants (POPs) convention and also global efforts to control lead in gasoline and elsewhere in the environment; 2) The Environmental Protection Agency (EPA) needs to overhaul its system for regulating chemicals, especially persistent ones like brominated flame retardants and perfluorochemicals; 3) Policymakers need to insist on strict adherence to existing laws that protect children from environmental hazards, such as the Clean Air Act, and not allow these laws to be weakened; and 4) The Food and Drug Administration (FDA) needs to create stronger measures to protect women of childbearing years and children from mercury exposures and other toxicants found in food.

Morning Plenary

Moderator: Ruth Hennig, Executive Director, The John Merck Fund

Presenters: Ted Schettler, MD, MPH; Science Director, Science and Environmental Health Network

Pete Myers, PhD; Founder and Chief Executive Officer, Environmental Health Sciences

Martha Herbert, MD, PhD; Pediatric Neurologist, Massachusetts General Hospital,Center for Morphometric Analysis/Pediatric Neurology

1) Ted Schettler, MD, MPH.—The Developing Brain: Vulnerability to Environmental Agents

Dr. Schettler stressed that children are uniquely vulnerable to environmental pollutants for a variety of biological and behavioral reasons. He noted that brain development begins early in fetal life and is not complete for years. This development depends on an orderly sequence of events that can be disrupted at many different points. The potential health implications of these disruptions depend on the timing and nature of the events, such as exposures to a specific toxin.

We have more information about the impacts of prenatal than postnatal exposures, although vulnerability extends into adulthood. A range of factors may interact and influence brain development at any given time, including single or multiple toxic agents as well as nutritional, social, infectious and genetic factors. In addition, cell division, migration, differentiation, synaptogenesis, myelination and pruning are subject to disruption by environmental agents, though the timing of the sequence of events differs in various parts of the brain. There is evidence from animal and/or human studies that different agents, such as mercury, ethanol, lead and so forth, act on these processes at different times. Dr. Schettler then presented specific research findings on the effects of lead, alcohol, nicotine, mercury, and PCBs on brain development. He concluded with several points: 1) extensive data exist on the health effects of about 12 neurotoxicants; 2) less extensive data on other compounds and agents that may impact brain development exist, but no data exist for the majority of chemicals to which people are commonly exposed and essentially none on the synergistic effects of simultaneous exposures to multiple chemicals; and 3) animal testing tends to underestimate the sensitivity of the human brain.

2) Pete Myers, PhD.— New Directions in Research: New Opportunities for Prevention

Dr. Myers opened by describing how we are now living "midstream" in a scientific revolution that is causing profound changes in how we think about the links between contamination and human health. He described what it means for a disease to be linked to a gene, including updated interpretations based on research on breast cancer and arsenic exposure. Dr. Myers described several mechanisms that can lead to changes in gene expression, including an example related to Down Syndrome whereby an environmental agent disrupts the normal chromosomal formation. He also presented several conceptual shifts in toxicology that are being forced into the field by new data coming from scientific studies: 1) some contaminants, even at extremely low exposure levels, can hijack control of gene expression; 2) when a disease is determined to be linked to genes, we also need to consider environmental factors if contaminants can alter that gene's expression; and 3) impacts on gene expression can occur at everyday levels. While DDT, PCBs, dioxin, lead, mercury and other substances remain as "bad actors," many more "modern-use" substances can also affect gene expression: pesticides like atrazine, plastics like bisphenol A, additives to plastics like phthalates, brominated flame retardants and surfactants like nonylphenol. Dr. Myers then noted that because diseases that were once thought to be only under genetic control may actually be influenced or even caused by environmental exposures, we now have the opportunity to prevent many diseases that heretofore have not been perceived as preventable except through genetic manipulation. This is good news. He added that we have shown with the Global POPs Treaty that society can decrease exposures once it reaches political consensus. He concluded that some remaining challenges include identifying compounds that interfere with gene expression and incorporating this scientific revolution into a new generation of public health standards.

3) Martha Herbert, MD, PhD.—The Science of Autism: Why We'll Never Understand Autism If We Don't Consider the Environment

Dr. Herbert began by stating that autism is a behaviorally defined syndrome and described shared characteristics of autism. She then noted that as Dr. Myers had suggested, there are likely genetic influences that interact with environmental factors to manifest as a cluster of behavioral characteristics known as autism. She shared information about suspected environmental agents

and described challenges to research in this area, especially the heterogeneity of the population and the difficulty of documenting real-life exposures. Dr. Herbert also described and compared various models of malfunctioning brains, noting one very intriguing finding that the amount of white matter in the brain of someone with autism is significantly larger than those who do not express that syndrome. Though the reason for this is yet unknown, this difference in the size and structure of the brain is significant. She then presented potential links between toxic substances and brain changes in autism, stressing that the impact of toxics is likely to be non-modular. She concluded with these points: 1) toxic substances can plausibly lead to abnormalities in brain development and manifest as behavioral characteristics known as autism, 2) studies on environmental toxicants can greatly help in understanding how and why autism occurs, and 3) the treatment of autism and the prevention of exposures that may lead to autism require attention to the mechanisms of environmental injury and gene-environment interaction.

Research Session I - Morning

Moderator: Steve Gilbert, PhD, DABT; Director, Institute of Neurotoxicology and Neurological Disorders

Presenters: Bruce Lanphear, MD, MPH, Director, Children's Environmental Health Center
Jennifer Nyland, PhD; Postdoctoral Fellow, Department of Environmental Health Sciences, Bloomberg School of Public Health, Johns Hopkins University
Isaac Pessah, PhD; Director, Center for Children's Environmental Health, University of California, Davis

1) Bruce Lanphear, MD, MPH – The Search for Environmental Causes of Learning Disabilities in Children

Dr. Lanphear, who studies how exposures to environmental toxins impact children's growth and development, focused his talk on two prevalent neurotoxins: lead and tobacco. He began by introducing what is known as the "epidemiologic triangle" to illustrate the interaction of agent, host and the environment in the etiology of diseases or conditions such as learning disabilities. Dr. Lanphear then articulated how focusing on environmental risk factors emphasizes prevention and presented an overview of parent-reported prevalence of Attention Deficit and Hyperactivity Disorder (ADHD) and learning disabilities from the National Health and Nutrition Examination Survey (NHANES) done in 1999 and 2000. He next described the various types of studies that are used to investigate causation: case, case series, case control, longitudinal cohort studies and experimental trials. Dr. Lanphear discussed the sequelae of lead toxicity, including mental retardation, seizures, cerebral palsy, optic atrophy and deficits in Intelligence Quotient (IQ) and reading scores. He noted that recommended levels for blood lead have been reduced repeatedly over the last several decades. Although questions remain, lead toxicity clearly contributes to learning disability in US children, including lowered intellectual ability and reading problems. In regards to tobacco smoke, exposures have been linked to low birth weight, conduct disorders, lower reading levels and asthma. There is evidence of gene-environment interactions between prenatal tobacco smoke and a genetic marker, a dopamine transporter (DAT), in the etiology of behavioral problems consistent with ADHD and oppositional behavior. There are numerous challenges to identifying environmental risk factors for learning disabilities. These include finding accurate biomarkers of fetal exposure, low detection for some toxins and the expense of longitudinal studies. Dr. Lanphear discussed using meconium as a biomarker and a new study

involving interventions for both lead hazards and injury control in children's homes. Though conducting research to identify risk factors for learning disabilities is daunting, he concluded by saying that gaining public support to eliminate environmental toxins that are already shown to influence brain development can help augment much needed research as well as stronger policies in this area.

2) Jennifer Nyland, PhD – Low Dose Mercury: Implications for the Nervous System

Dr. Nyland opened by stating that the main source of exposure to mercury is through consuming contaminated fish. Mercury exposure, which can occur throughout the lifetime of an individual beginning with fetal development, can cause decreased immune responses, autoimmune dysfunction and neuroimmunotoxicity. Mercury is also a cofactor for susceptibility to disease, changing thresholds of activation for immune cell responses to stimulation. She then noted that studies on prenatal exposure to low levels of mercury in mice show lasting effects in the adult immune system, with the changes dependent on gender. Neuroimmunotoxicity studies indicate that mercury inhibits neural migration in the developing brain and modulates gene expression. There is no evidence, however, for mercury-induced frank autoimmune disease in humans or in mice at the low levels discussed. Dr. Nyland concluded that low doses of mercury can cause lasting changes in the immune and nervous systems of mice and that the interaction between genetic susceptibility and environmental agents in terms of disease manifestation is another important area of research.

3) Isaac Pessah, PhD – GABAa Receptor Deficiency Significantly Potentiates Excitotoxicity of Non-coplanar PCB170 in the Acute Hippocampal Slice Preparation

Dr. Pessah first mentioned that from 1999 to 2002 the number of cases of severe autism in children up to three years old doubled in California. He stated that not all of the increase can be explained by diagnostic drift or immigration. He then described autism as a developmental disorder whose severity may involve a complex interplay of genetic and environmental factors. More than 15 different genes are thought to contribute to childhood susceptibility, and several candidate genes are associated with autism spectrum disorder. Identifying a candidate gene that codes for a protein in the family of the GABA-receptor subunits within the brain underscores the potential interplay of genes and environment. The primary role of GABA-receptors after birth is to prevent the brain from becoming overexcited. Many autistic children also suffer from seizure disorders that may at least in part be due to insufficient GABA receptor activity. Many pesticides are known to directly block the activity of GABAa receptors. In addition, environmentally persistent pollutants such as PCBs are neurodevelopmental toxicants that can augment exitotoxic response. Dr. Pessah then described a study of rats which revealed that a combination of GABA-receptor block and exposure to non-coplanar PCBs (i.e., those molecularly unlike dioxin) greatly enhanced excitotoxicity in a region of the brain called the hippocampus. In vitro, PCB exposure enhanced the gain of excitatory and inhibitory circuits. With maternal exposure to PCBs from gestation day five through postnatal day 21 (when the baby rats were weaned), Dr. Pessah has found that the hippocampus from treated animals were extremely more sensitive to subsequent exposure to GABA blockers and resulted in seizure-like wave forms. These data indicate that a deficiency in GABA signaling in the brain can be significantly magnified by exposure to environmental levels of POPs such as PCBs and enhance seizure-like activity in the brain. Dr. Pessah concluded that these studies provide a rationale for exploring the influence of genetic deficiencies in GABA-receptor activity, such as those associated with autism on chromosome

15q11-12 and exposure to environmental toxicants. Moreover the findings raise the question as to whether certain children with autism are more susceptible to the excitotoxic effects of environmental chemicals.

Education Session I - Morning

Moderator: Michele Gagnon, Environmental Health Project Director, American Association on Mental Retardation

Presenters: David Wallinga, MD, MPA; Co-Director, Food and Health Program, Institute for Agriculture and Trade Policy

Barbara Sattler, RN, DrPH; Director and Associate Professor, Environmental Health Education Center,University of Maryland School of Nursing

Jo Behm, RN, MS; Past President, Governmental Relations and Legislative Action Chair, Learning Disabilities Association of California

1) David Wallinga, MD, MPA – Neurodevelopmental toxins: More Science, and the Context of Science

Reviewing themes and information presented in *In Harm's Way*, Dr. Wallinga discussed indicators that chronic childhood disease and disabilities are widespread, including learning and developmental disabilities (LDDs). There are multiple contributors to LDDs in children, with environmental contributors important and preventable. Toxicity discovered at high doses should be a "red flag" for possible harm from lower-dose or "background" levels of exposure. Dr. Wallinga reviewed research regarding low-dose effects of PCBs, lead, mercury, pesticides, insecticides and polybrominated dipenyl ethers (PBDEs or flame retardants). Evidence of harm from these substances is only the tip of the iceberg; there are many more chemicals that are undertested or untested, yet which are produced in the millions of pounds per year. Dr. Wallinga discussed the Centers for Disease Control's (CDC's) recent biomonitoring study which analyzed the "body burden" of 116 chemicals in people around the country. He also noted recent reports from Pesticide Action Network North America (PANNA) and the Environmental Working Group regarding body burdens of chemicals in people. Though he noted it is not clear yet what the health implications are of these chemical body burdens, the fact that most of these chemicals did not exist 60 years ago and that we are currently seeing major increases of many chronic diseases and disabilities (very likely related to environmental pollutants) suggest that these chemicals in our bodies are impacting our health. He addressed several cultural assumptions about chemical risks and emphasized that with the slow rate at which "proof" of harm materializes, generations of children can be at risk before an adequate regulatory response occurs. Dr. Wallinga emphasized that protecting children from neurotoxic threats will require a regulatory system capable of preventing rather than simply reacting to widespread exposures and harm. Action needs to be based on prevention, such as in the Rio Declaration and Registration, Evaluation and Authorisation of CHemicals (REACH), the proposed European Union plan to test the most widely used chemicals for impacts on human health.

2) Barbara Sattler, RN, DrPH – Environmental Health Risks in our Everyday Lives

Acknowledging what previous speakers had described as the links between health risks and environmental contamination, Dr. Sattler focused on three areas: 1) common environmental contaminants in our everyday lives; 2) new studies evaluating our body burden of potentially harmful environmental toxicants; and 3) what steps we can take to reduce environmental risks to

ourselves, our families and communities. She first emphasized that our policies and practices are not keeping up with our scientific knowledge of the health risks associated with environmental hazards. She emphasized that a new and expanded focus must be developed to "translate" the emerging science into policies and practices that truly help to protect public health. Building on Dr.Wallinga's description of the CDC's biomonitoring study, she noted these and other studies that sample urine, blood, hair and breast milk help us to understand that the environment is not something abstract and "out there" but rather that **we** are the environment – our bodies are a direct reflection of the pollutants in our air, water and food. In this light, Dr. Sattler stressed that there is a critical need to accurately and effectively communicate information about reducing risks. For example, there are often environmentally healthier choices for the products that we use, such as paints with low Volatile Organic Compounds (VOCs), non-toxic pest control choices and mercury-free hospital equipment. The "science" of risk communication and "marketing" of public health information, however, needs to catch up with the environmental health sciences regarding public health risks. Our health care providers are poorly prepared in the area of environmental health and consequently cannot be relied upon to provide the missing information. We need to develop a national public health strategy for better identifying potentially hazardous chemicals in our consumer products, energy production, industrial processes and agricultural practices and for helping the public to become informed consumers and advocates for their own environments. Dr. Sattler presented an overview of sources of environmental health exposures in homes, communities, and places of play and work, including lead, mercury, pesticides, indoor and outdoor air pollution. For an online article that addresses the issues that Dr. Sattler covered, see http://nursingworld.org/mods/mod370/cehcver.htm (EH in Health Care Setting), http://nursingworld.org/mods/mod290/cehmvers.htm (EH Homes and Communities), or http://nursingworld.org/mods/mod250/CESAVERS.HTM (EH Schools).

3) Jo Behm, RN, MS – Importance of Taking Personal & Agency Inventory and Getting Organized As First Steps Toward Engaging Critical Mass

Ms. Behm introduced herself and how she became concerned about these issues as a mother, a nurse and policy advocate. She noted that the essence of the problem is that developmental, learning, behavioral, and mental health disabilities, illness, and chronic disease are increasing at staggering rates, impacting vulnerable infants, children and teens. Environmental chemical exposure contributes significantly to this public health crisis but toxicity data and industry accountability are woefully lacking. Ms. Behm reviewed sources of toxins, their routes of exposure and effects on health. She then presented actions to take—from the personal to the policy levels and from local to federal levels. Next she presented a list of questions to ask of yourself, your agency/organization, and your partners/collaborators regarding the links between environmental pollutants and learning and developmental disabilities and what may or may not be happening to address these issues. She stressed that the timing is urgent and the need is widespread. Ms. Behm concluded that everyone who can should help, but for lasting and durable momentum and impact, leaders and larger agencies must take sufficient time to take inventory, organize, and, above all, collaborate in order to protect children from these environmental hazards.

Advocacy Session I - Morning

Moderator: Sharon Davis, PhD; Director of Professional and Family Services, The Arc of the United States

Presenters: Betty Mekdeci, Executive Director, Birth Defect Research for Children, Inc.
Sallie Bernard, Executive Director, Safe Minds
Sandy Cort, Board Member and Past President, Learning Disabilities Association of Maine

1) Betty Mekdeci – Patterns of Functional Deficits Identified in Vietnam Veterans' Children

Ms. Mekdeci gave a brief history of the development of the National Birth Defect Registry, a project of Birth Defect Research for Children, Inc. Data collection for this project includes recording both structural and functional birth defects as well as exposures of both parents both before conception and before birth. The registry is based on the concept of the "Alert Practioner," – doctors who have observed similar patterns of birth defects in their patients have looked for and found similar exposures in the prenatal histories. The majority of teratogens, including thalidomide, radiation, rubella, Dilantin, DES, alcohol, methylmercury and others, have initially been identified through this process. The National Birth Defect Registry has used computer technology and an interrelational database design to adapt this concept to data collection on a large scale. National birth defect issues evaluated through the registry include the antinausea medication Bendectin, Agent Orange, toxic exposures during the Gulf War, and toxic exposures on a community level in the US. Ms. Mekdeci's presentation focused on the pattern of functional disabilities that the registry has identified in the children of Vietnam veterans, including increases in learning and attention disorders, chronic skin problems, allergic conditions and immune and endocrine disorders. This pattern is consistent with animal, cell culture and human research showing that Tetrachlorodibenzo-p-dioxin (TCDD), the dioxin contaminant of Agent Orange, is linked to dysfunction of the immune system, ectodermal effects, neurobehavioral effects, thyroid defects, abnormalities of teeth and alterations in learning. Ms. Mekdeci then mentioned that research described in a 1987 Report to Congress indicated that the normal prenatal development and functioning of the immune system may be important in the development of learning disabilities. In addition, current research is revealing the importance of prenatal thyroid levels in neurological development. She concluded by stating that research for the registry leads to the possibility of redefining a birth defect to include not only structural abnormalities but abnormalities of the systems that run the body – the neurological, immunological and endocrine systems – and which may lead to other health problems. For more information, see www.birthdefects.org.

2) Sallie Bernard – Advancing Our Understanding Regarding Mercury-Induced Neurological Disorders

Ms. Bernard is the cofounder and executive director of SafeMinds (Sensible Action For Ending Mercury-Induced Neurological Disorders), whose primary focus is on autism and thimerosal, a mercury-based preservative in vaccines. Ms. Bernard first reviewed various mercury-poisoning disasters: food poisonings from seed dressings in Iraq, Russia, and China; fish contamination in Minamata and Niigata, Japan; industrial/occupational exposures and medical exposures. She then described the history of autism, its characteristics and its prevalence. Recently thought to be genetic, she noted that autism is now regarded as a manifestation of gene-environment interactions. Ms. Bernard next reviewed the use of thimerosal in vaccines and the lack of safety

studies regarding it. She also highlighted the formidable challenges that remain: 1) working against powerful constituencies such as companies that make vaccines, 2) the lack of research on repeat injections of thimerosal on human infants, 3) that fact that mercury research has primarily focused on prenatal methylmercury exposure from fish and not on other sources of mercury exposure, and 4) SafeMinds is a small group with a limited budget and the problem is large and widespread. She next reviewed research funded by SafeMinds as well as their efforts to foster understanding and policy initiatives. In conclusion, Ms. Bernard said she believes that proving the link between thimerosal and autism will lead to prevention, and determining the mechanisms and pathways of exposures will also lead to treatments and cure.

3) Sandra Cort – Advocacy Efforts: A State Perspective

Ms. Cort is on the board of directors of the Learning Disabilities Association of Maine (LDA-ME), an affiliate of the Learning Disabilities Association of America (LDA). There are 540 members, including parents of children with learning disabilities. LDA-ME is also a grant-funded partner of the Alliance for a Clean and Healthy Maine (ACHM). The goals of the Alliance are to support legislation to promote safer alternatives to persistent toxic chemicals, to educate the public to reduce human exposure to harmful chemicals, and to oppose attempts by toxic polluters to circumvent environmental health laws. ACHM supported two bills to reduce mercury in Maine's environment in 2002, two bills to reduce mercury in 2003 and one mercury bill in 2004. LDA-ME's activity on these bills has led to their participation in national LDA's Healthy Children Project. She then highlighted some current challenges: 1) research shows that the average person does not know about and does not become aware of information about mercury until something goes wrong in his or her life or in the life of someone close to them, 2) there isn't a precautionary decision-making system that ensures toxic materials are not put on the marketplace in the first place, and 3) people don't know about available alternatives. She concluded by stressing that public action is important to ensure businesses, government and other organizations do what is right in terms of protecting public health. There are many people in decision-making positions that don't understand and don't believe the data. LDA-ME's work, along with their partner organizations, is to convince the right people that there is a problem.

Afternoon Plenary

Moderator: Stewart Hudson, President, Emily Hall Tremaine Foundation
Presenters: Doreen Croser, Executive Director, American Association on Mental Retardation
Jane Browning, Executive Director, Learning Disabilities Association of America

1) Doreen Croser – Collaborating for Action: Pollution, Toxic Chemicals and Mental Retardation

Ms. Croser opened with an overview of the American Association on Mental Retardation (AAMR): its history, membership and mission to support disability professionals through research, education/training programs and tools for the field. AAMR works to advance progressive policies and collaborate with network partners: prevention has been an issue for decades and ties in with the growing national and international interest in the relationship between disabilities and the environment as well as a focus on promoting good health. Ms. Croser summarized the importance of environmental health issues and why AAMR is working to collaborate with interested organizations. She then provided an overview of the summit AAMR organized at the Wingspread Conference Center last summer. At the meeting, research regarding environmental pollutants and brain development, common concerns, shared values and

collaborative opportunities were all discussed. Ms. Croser noted the one of the main goals of the conference was framing a national blueprint for promoting health and preventing exposures that might lead to mental retardation and developmental delays. She then presented AAMR's plans to implement the blueprint specifically by designing strategies and actions through the newly formed Education, Training & Outreach Action Committee, Research & Science Action Committee, and Policy & Legislative Action Committee. She concluded with AAMR's goal: making our world a healthier place for all by reducing environmental pollution that may lead to or exacerbate disabilities.

2) Jane Browning –David v. Goliath: Grassroots Advocacy on Behalf of Children's Health

Ms. Browning expressed great satisfaction that the LDD field is in the midst of a revolution—a revolution in how groups think about disabilities in terms of what we can do to prevent environmental threats to brain development. She acknowledged the contributions of many participants in the room towards instigating this revolution, particularly the work of Audrey McMahon and the Learning Disabilities Association (LDA) Research Committee. She also acknowledged the John Merk Fund and Heinz Endowment for their support. Ms. Browning then noted that reducing the incidence of learning disabilities is one of the four major goals of the LDA and the recent development of the LDA's Healthy Children Project (HCP), led by Kathy Lawson, is one of the major ways LDA is trying to reach that goal. HCP is devoted to educating LDA constituencies about links between neurotoxicants and LDs and encouraging appropriate policy actions to eliminate neurotoxicants and better protect children's health. Through HCP, several state chapters of LDA have developed environmental health programs with other organizations, including environmental health groups. Some state chapters that are HCP partners include Maine, which is focused on mercury legislation; New York, which is focused on lead issues in the Buffalo area; and California, which is focused on banning PBDEs. Ms. Browning stressed the need to let state projects grow in their own ways depending on the concerns and needs in each area. The national LDA office serves as a hub for communications among grass-roots initiatives to exchange materials, ideas and strategies. As part of this effort, the national office is also working to link the LDA research community with the research community of The Arc and AAMR. Ms. Browning then shared a news article titled, "Industry Fears Growing Role of Patient Groups in Environment Lobby" from *The Christian Science Monitor* that indicates that the National Petrochemical Refiners' Association is paying attention to and concerned about the recent transformation of environmental issues to include public health concerns. She noted that this means we are doing our work well.

Research Session II - Afternoon

Moderator: Pete Myers, PhD; Founder and Chief Executive Officer, Environmental Health Sciences

Presenters: Michael Friedlander, PhD; Director, Civitan International Research Center, University of Alabama at Birmingham School of Medicine
Sarah Knox, PhD; Behavioral Scientist, The National Children's Study, Division of Epidemiology, Statistics and Prevention Research, National Institute of Child Health and Human Development, National Institutes of Health
Tom Zoeller, PhD; Professor, Biology Department, University of Massachusetts-Amherst

1) Michael Friedlander, PhD – PCBs and Neural Development: Hijacking the Brain's Pathways

Dr. Friedlander emphasized that timing is extremely important in brain development and that critical periods extend well beyond the gestational period throughout postnatal life and even throughout puberty. He then went on to describe a case study in Alabama that demonstrates on a community level how neurotoxicants can undermine healthy development. About 1.5 billion pounds of PCBs were dumped in two unlined landfills near Anniston, Alabama, from the 1930s to 1961.While there have been legal actions and settlements, there has been no local comprehensive health investigation of residents to date. Exposures may be through less well-investigated routes such as inhalation of volatized PCBs, along with the better understood routes from soil and water exposure and ingestion of contaminated fish. The research team at the University of Alabama at Birmingham's Civitan International Research Center (led by Dr. Alan Percy, a Pediatric Neurologist; Dr. Fred Biasini, a developmental psychologist; and Dr. Michael Friedlander, a developmental neurobiologist) is part of a consortium with seven universities. This team will measure and evaluate congener and metabolite patterns in PCB-exposed people and families. Specifically, they will study the health impacts and neurocognitive function of children, including sensory and motor processing, behavioral problems, academic performance and higher neurocognitive processes such as the brain's executive function. In addition, there is a growing body of evidence that suggests that PCB exposure can affect a number of key signaling pathways in neurons in the developing brain. These include 1) calcium signaling mechanisms that can activate cellular changes, such as programmed cell death that may occur at inappropriate times; 2) the nitric oxide (NO) signaling system that plays a role in learning and memory and development of a wide range of behaviors, such as sexual behavior and maternal behaviors; 3) nuclear regulatory elements (CREB) that control gene expression in response to environmental cues; and 4) synaptic changes that contribute to learning and the formation of new memories, such as long term synaptic potentiation. If these patterns of activation are inappropriately timed, this may lead to "nonsense" signals that confer "plasticity" to circuits in the developing brain or eliminate connections at the wrong time and/or place for normal development to proceed.

2) Sarah Knox, PhD –National Children's Study: A Longitudinal Cohort Study of Environmental Effects on Health and Development in Children

Dr. Knox first provided some background information on chemicals in the environment. She noted that more than 80,000 chemicals are registered with the EPA, with 3000 chemicals showing a use of at least a million pounds per year. Only 43% of these 3000 chemicals have received even minimal study relating to their effects. She stressed that there is also a lack of epidemiological studies with a developmental perspective, a lack of studies with animal models and a lack of studies that include behavioral endpoints and neurobehavioral outcomes. Proposed in 1998 and authorized in 2000, the National Children's Study (NCS) is designed to fill some gaps in our understanding of chemical, physical, behavioral, social and environmental influences on health and development. NCS will enroll 100,000 pregnant women and follow their children for 21 years. It will track fetal growth, birth defects, growth, nutrition and physical development, medical conditions such as asthma, injuries, cognitive and emotional development, and mental, developmental and behavioral disorders. Work groups are now in the process of prioritizing and developing the protocols for the studies to be undertaken. NCS is particularly committed to making sure the study remains independent and is not influenced by special interests. She concluded by saying that many countries have expressed interest in the NCS as well, and she

hopes the results will provide much needed data for researchers, governments, public health officials and health care providers around the world.

3) Tom Zoeller, PhD –Research Opportunities/Needs: Thyroid Hormones and Brain Development

Dr. Zoeller presented studies of maternal thyroid hormone insufficiency and the impact on brain development. The studies he described included both clinical and subclinical (mild) hypothyroidism as indicated by high levels of Thyroid Stimulating Hormone (TSH) and low levels of thyroid hormone in the blood. He noted that the prevalence of clinical hypothyroidism is about 0.3% of pregnant women, with about 10 times as many subclinical cases. This means about 132,000 babies are born each year to women with a deficiency in thyroid hormone. Effects of low maternal thyroid hormone exposure include lower IQ, attention deficits, impaired visual processing and motor function. The severity of these effects is related to the severity of the insufficiency. The domains affected depend on the timing of the insufficiency. With these outcomes, and considering that women with a preexisting hypothyroid condition are recommended to increase their thyroid hormone dosage by 50% when they become pregnant, Dr. Zoeller wondered why there is no screening program for thyroid function for pregnant women. The argument against screening pregnant women involves the lack of evidence that thyroid hormone replacement will fix these problems; however, pregnant women taking exogenous thyroid hormone exist in sufficient numbers for this evidence to be available. Dr. Zoeller then described how environmental chemicals can affect thyroid hormone, reducing thyroid function or interfering with the way thyroid hormones act on the developing brain. Thyroid disrupters include PCBs, DDT, dioxins, perchlorates, methylmercury, herbicides and pesticides. He concluded by acknowledging the complexity of determining exactly how and in what doses these chemicals can impact brain development. For example, PCBs are similar in structure to thyroxine, but the effects of PCBs on the brain are not similar to those of thyroxine.

Education Session II - Afternoon

Moderator: Ted Schettler, MD, MPH; Science Director, Science and Environmental Health Network

Presenters: Sharon Davis, PhD; Director of Professional and Family Services, The Arc of the United States

Kathy Lawson, Program Director, Healthy Children Project, Learning Disabilities Association of America

Wendy Nehring, RN, PhD, FAAN; Associate Dean for Academic Affairs, Director of Graduate Programs, and Associate Professor, College of Nursing, Rutgers, The State University of New Jersey

1) Sharon Davis, PhD –Outreach Strategies of The Arc of the United States

Dr. Davis began by presenting the mission, goals and other information about The Arc. A grassroots organization with approximately 120,000 members affiliated through 900 state and local chapters, The Arc advocates for children and adults with cognitive, intellectual and developmental disabilities. Advocacy is accomplished by education and information dissemination, national outreach and work on public policies. The Arc also helps to organize an annual public policy seminar, held jointly with four other organizations, advocating for people with developmental disabilities. Joint projects include collaboration with universities and other

agencies and a national health promotion and disability prevention committee. The Arc's strategies specific to environmental health include joining LDDI, participating in AMMR's Wingspread conference and signing on to the letter regarding concerns about mercury pollution. Other interests include looking at environment and laws regarding exposures in sheltered workshops.

2) Kathy Lawson –Healthy Children Project: Know More and Do More for Environmental Health

Ms. Lawson opened by stating that the Healthy Children Project (HCP), a program of the Learning Disabilities Association of America (LDA), was launched in discussions with LDDI. The goals of HCP include 1) advancing knowledge about the science linking neurotoxicants and learning and developmental problems; 2) producing a website, fact sheets, speakers' bureau, databases, listserv and newsletter; and 3) advocating collective action as a powerful tool for policy change. Several state chapters of the LDA have become HCP partners. Elaborating on Ms. Browning's presentation about HCP during the afternoon plenary, Ms. Lawson noted that HCP initiatives include LDA-California's support for various state legislative efforts on specific neurotoxicants; LDA-New York's support for policies to create environmentally healthier schools as well as studies regarding landfills and lead exposures; LDA-Maine's legislative work on no less than five environmental health bills; and LDA-Washington's collaboration with the Institute for Children's Environmental Health (ICEH) on the Healthy Futures Program engaging teens in environmental health education. Ms. Lawson concluded by mentioning that HCP partners for Year II are LDA affiliates from Alabama, Arkansas, Georgia, Iowa, Michigan, Missouri, New Jersey, Oregon and Texas, all of which will play a unique role in outreach, education and action to reduce the health risks of environmental hazards for our children.

3) Wendy Nehring, RN, PhD, FAAN –Education for Professionals Who Specialize in Intellectual/Developmental Disabilities

Dr. Nehring opened by stressing the need for awareness and reexamination of prevention of mental retardation from the micro-levels (genetics) and the macro-level (environment). Past emphasis in this field has been on the interplay of genes and environment with substances such as alcohol, lead and drugs. More recent interests emphasize emerging work with mercury, smoking and other environmental pollutants. Disability concerns that are often in the news include autism, ADHD, asthma and cleft lip/palate, but Dr. Nehring said that current scientific literature has few articles relating environmental exposures to intellectual and developmental disabilities (I/DD). She then articulated a number of questions that those of us concerned with these issues need to ponder: What are the potential and additional risks for ethnic and racial groups who have mental retardation? What is the relationship between the incidence of I/DDs and socioeconomic status? How do genes and environment interact in ways that influence the development of I/DDs? What are the risks to adults after they have had a childhood exposure to lead, for both short- and long-term health impacts? What should we do about the lack of healthcare standards and guidelines? She then emphasized that we need to examine settings where people with I/DD spend time and to look at economic impacts. In addition, we need to raise awareness through education, develop research priorities regarding I/DD and the environment, pursue policy opportunities where appropriate, and enhance our partnerships with the multiple experts in different fields who work with people with I/DD. She concluded by

saying that self advocates and family members also need to be included in the development of educational and research initiatives.

Advocacy Session II - Afternoon

Moderator: Amy Kostant, Program Director, Environmental Media Services
Presenters: Monica Moore, Co-Director, Pesticide Action Network North America (PANNA)
John Balbus, MD, MPH; Director, Health Program, Environmental Defense Fund
Steve Boese, MSW; New York State Director, Healthy Schools Network, Inc.

1) Monica Moore –Developing Stronger Partnerships for Better Public Health Research and Policy

Ms. Moore opened by providing some background on PANNA, whose primary focus is on research and coalition building around pesticides and public health. She noted that working on pesticide issues is a useful way of bringing the environment and health fields together. Building effective partnerships with children's environmental health groups as well as LDD groups is key. Although creating good partnerships takes more wisdom and effort than working individually or as a single group, they can work and have greater expediency. Ms. Moore then described different types of partnerships and structural forms. She noted that important elements of partnerships include having common interests and values, setting clear goals and objectives, being persistent, staying focused, dealing well with differences and acknowledging when to terminate a partnership (with grace). Ms. Moore also spoke about changing the role of research and the need to translate the latest science into strong public policy not only with other advocacy groups, but with researchers. Along these lines, she suggested that we need to address how corporations shape scientific inquiry and results. She also recommended that we should put more emphasis on using and developing alternatives rather than only focusing on hazards and risks. She concluded by saying that new tools, concepts and methods for this work include: 1) using the precautionary principle to guide the decision-making process; 2) biomonitoring of people regarding chemical exposures; 3) and targeted action campaigns on specific "bad actors," such as Dursban.

2) John Balbus, MD, MPH – Healthy Brain Partners: LDDI and Environmental Advocacy Groups

Dr. Balbus opened with an overview of the Environmental Defense Fund and noted their publication "Toxic Ignorance" and their scorecard website (www.scorecard.org). Visitors to that site can obtain a report about pollutants and health data in their communities by simply typing in their zip code. This site can be particularly useful to grassroots health groups working on environmental health issues in their communities. Dr. Balbus then spoke of the need to "sharpen the tools" of neurotoxicity research to enhance public policies to protect children from neurotoxics. He mentioned that current testing protocols may not be sufficiently sensitive to detect subtle neurodevelopmental toxicity, and the identification of recognized neurotoxins is inadequate. The teaming of environmental and children's advocacy groups creates a stronger voice for additional research funding and regulatory advocacy. The history of health groups' influencing research funding and agendas suggests that having the messages come from health groups, rather than just environmental groups, has more impact. He concluded by saying that the establishment of LDDI bodes well for all of us concerned with environmental pollution and LDDs.

4) Steve Boese –Creating Healthier Learning Environments for All Children

Mr. Boese opened with an overview of the Healthy Schools Network (HSN), a not-for-profit advocacy organization which is a coalition of parent, environmental, health, labor and education groups dedicated to assuring every child and employee has access to an environmentally healthy school. He added that HSN acts as a clearinghouse and provides NewsSlice, an online service with news clips, conferences and research. Recently, HSN also helped draft a national position statement on healthy schools with National Healthy Schools Coalition partners and created a National Healthy Schools training binder. Mr. Boese then reviewed the "Guiding Principles of School Environmental Quality," developed by HSN, which includes child, parent, and employee rights and school and government responsibilities. He stressed that schools should be viewed as workplaces not just for adults, but for children. Schools are unique environments because children are required to attend regardless of local hazards or conditions and there is no tracking or reporting of child illness or injury at school. The Occupational Health and Safety Administration (OSHA) may protect adults on the job, but not children at school. Hazards in schools include indoor air pollution; molds; lead; arsenic; mercury; pesticides and other toxic products; and poor plumbing, wiring and lighting. These exposures can impact how well children are able to think and learn. It is hard to address these issues because there is a repair crisis in our schools including widespread ventilation problems, poor lighting, poor heating, indoor air quality and acoustics. In fact, Mr. Boese stated, schools are in worse shape than prisons, with estimates of $127 billion to $254 billion needed to construct and to fix buildings, even without adding technology. Parents and public health officials are not usually in school facilities daily and may be unaware of problems or how to solve them. Teachers and support staff, including custodians and nurses, often see the problems and may know who is affected, but are not asked. Most building professionals do not have expertise in children's environmental health so they don't know what to look for. In that light, he stressed the need for stronger federal regulations and necessary funding to rectify this situation. He concluded by reviewing recent federal activities, including the failure to renew the 2000 Appropriations for School Renovations, bond allocations to states, and the Healthy and High Performance Schools Act.

Final Wrap-Up

Elise Miller moderated a discussion of the day's progress and activities. She began by reiterating the charge that she gave to participants at the beginning of the day: How can we more effectively integrate research, education and advocacy in order to protect children from neurotoxicants that may undermine their capacity to reach their fullest potential?

She then briefly reviewed some suggestions that emerged from the day's discussions. These included:

Research

- Research additional environmental factors that can influence brain development.
- Develop research priorities regarding how combinations of chemicals can impact brain development and gene-environment interactions.
- Have a follow-up conference devoted solely to energizing science on environmental contributors to LDDs.

Education

- Ensure educational materials are well-grounded in solid science.
- Reduce exposures to environmental pollutants to protect health.
- Make sure health professionals are aware of these issues so they can adequately and accurately inform their patients.
- Create interdisciplinary teaching tools that can be used in a variety of settings.
- Develop core messages that all groups can use.

Policy/Advocacy

- Implement better tracking systems for LDDs across the country.
- Translate current and emerging science into stronger public policies that actually protect people, particularly children and those already with LDDs.
- Implement and sustain strong regulations on substances we already know harm health, such as POPs.
- Support legislation that provides appropriations for further research.
- Build stronger collaborations through LDDI on specific policies such as mercury and pesticides and ensure those partnerships are developed with clear and open communication among participating groups.
- Create advocacy models that can be replicated in other states.
- Use the precautionary principle as a basis for decision-making (pass more precautionary principle resolutions across the country).

Additional comments and suggestions from participants during the final session included:

1. We need to undertake research on health care and other economic costs of having increasing numbers of people with LDDs.
2. We should take care of those with LDDs in interdisciplinary ways by including not only toxics, but diet, movement and other therapies in our discussions.
3. About 70% of respondents in a Research America survey said they approve of supporting biomedical research, but the support is not so large for "environmental" health research. Part of the reason may be that politicians respond negatively to funding requests for anything having to do with the environment. In this context, we need to refine our terminology for better marketing and packaging of our message to increase effectiveness—such as using the phrase "public health" rather than "environmental health."
4. We need resources, particularly short (10 minute) videos, that articulate these issues in order to help educate communities and policymakers.
5. We should create more opportunities to bring together communities and scientists. Scientists are often viewed as the "bad guys" because science has been used to obfuscate remediation. We should support community-based research and communities where science has been used to delay action.
6. When we talk about LDDs, we should worry less about labels and more about individual symptoms or behavioral characteristics.
7. We need to realize that science has brought in many of the problems that we're addressing and emphasize the distinction between what science has produced and what science can solve.

Elise Miller concluded the conference by warmly thanking the John Merck Fund, the speakers, her staff and other volunteers who worked behind the scenes, and the audience members for their engagement throughout the day and their ongoing commitment to the issues. She noted that the proceedings from all the sessions will be compiled and distributed to all participants. She then thanked the LDA for helping to make arrangements for people who planned to visit congressional leaders on Capitol Hill the following day and indicated where those people should meet in the morning. Finally, she emphasized how much she looked forward to working with everyone to further the ideas and suggestions developed at this meeting.

Appendix: Abbreviations and Acronyms

AAMR	American Association on Mental Retardation
ADHD	Attention Deficit Hyperactivity Disorder
CHE	Collaboration for Health and the Environment
DDT	Dichloro-diphenyl-trichloroethane
DAT	dopamine transporter
EPA	Environmental Protection Agency
FDA	Food and Drug Administration
I/DD	intellectual and developmental disabilities
HCP	Healthy Children Project
IQ	Intelligence Quotient
LDA/LDAA	Learning Disabilities Association of America.
LDAME	Learning Disabilities Association of Maine
LDD	learning and developmental disability
LDDI	Learning and Developmental Disabilities Initiative
NHANES	National Health and Nutrition Examination Survey
PANNA	Pesticide Action Network North America
PBDE	polybrominated dipenyl ether
PCB	polychlorinated biphenyl
PFC	perfluorochemical
POP	persistent organic pollutant
REACH	Registration, Evaluation and Authorisation of CHemicals
TCDD	Tetrachlorodibenzo-p-dioxin
TSH	Thyroid Stimulating Hormone
VOC	Volatile Organic Compound