

LEARNING AND DEVELOPMENTAL DISABILITIES INITIATIVE

MEETING NOTES

CITY CLUB, WASHINGTON, DC
MARCH 21, 2003

Participants:

Jeremiah Baumann, *State Public Interest Research Groups*
Jo Behm, *Learning Disabilities Association - CA*
Jane Browning, *Learning Disabilities Association of America*
Sandra Cort, *Learning Disabilities Association - ME*
June Crawford, *National Institute for Literacy*
Doreen Croser, *American Association on Mental Retardation*
Sharon Davis, *The Arc of the United States*
Mark Dubin, *Communities Against Violence Network*
Ruth Hennig, *John Merck Fund*
Ron Hume, *Learning Disabilities Association of America*
Amy Kostant, *Environmental Media Services*
Kathy Lawson, *Learning and Developmental Disabilities of America*
Patty Lemer, *Developmental Delay Resources*
Elise Miller, *Institute for Children's Environmental Health*
Pete Myers, *United Nations Foundation and Commonwealth*
Pam Nesbitt, *YAI/New York League for Early Learning*
Neil Payne, *Clean Water Fund*
Tanya Shuy, *National Institute for Literacy*
Larry Silver, *Learning Disabilities Association of America*

Welcome and Introductions

Elise Miller welcomed everyone and reminded participants of the broad goals for the draft 2003 strategic plan of LDDI as articulated on our conference call in January, 2003:

1. Develop a resolution that would serve as both an organizing tool for LDDI and a document for influencing policymakers;
2. Heighten media on this issue;

3. Strengthen the experience of the LDD sector as a collective:
 - Formulate our ideas in ways that reflect the joint interests (i.e., reducing environmental impacts on the developing brain) of all groups in order to leverage our collective capacity to educate broader constituencies and change state and potentially national policies. By strengthening the sector as a whole in the area of prevention, it will in turn strengthen each organization with its particular focus and mission.
 - Identify distinct projects that would be useful for all of us to work on together. Show how our collective work is value added for their individual organization's work. Initially use the resolution and CDC report as organizing tools, and formulate similar opportunities for collaboration, such as a particular policy initiative, aiming for at least one a quarter;
4. Continue Outreach to other LDD organizations; and
5. Underscore working models and deepen engagement through face-to-face meetings.

Elise then highlighted the overall goals for the March 21 meeting:

1. learn more about the latest science regarding toxicants and brain development;
2. highlight the LDA's and AAMR's initiatives to serve as possible models for other LDDI member organizations;
3. determine how to engage other LDD organizations not already active in LDDI;
4. review and refine LDDI draft resolution;
5. discuss other emerging projects and initiatives including policy and media opportunities;
6. further define the role and parameters of the LDDI's new sub work group, known as the Criminal Justice Work Group, headed by Jane Browning;
7. refine specific strategies for the upcoming year of LDDI activities.

Participants then introduced themselves.

Overview of the Science

Pete Myers, PhD, provided an overview of the science on neurotoxicants and brain development. Some highlights:

- Limited knowledge: Too few compounds tested, particularly at low doses; no realistic look at health impacts of mixtures of compounds; and very little epidemiology that can rule out causal relationships between exposures and health outcomes. In essence, as researchers, “we're still looking just under the lamp post” and not at broader and more complex relationships between neurotoxicants and brain development.
- Case studies on neurotoxicants, including organophosphates, PBDEs, PCBs, bisphenol A, and arsenic. Reminder: animal studies generally under predict human sensitivities.
- Understanding the relationship between heredity, genes and the environment: We may inherit particular genes, but environmental exposures can influence gene expression (can activate or deactivate genes inappropriately) not just phenotype. This means that the environment can affect heredity, genes and output of gene expression to determine who we become.

Overview of Model Programs

Learning Disabilities of America's Healthy Children Project

- Jane Browning, Executive Director

Jane gave an overview of the Healthy Children Project (Kathy Lawson was not feeling well enough to present.)

National Office

- Formulated Advisory Committee
- Convened Advisory Committee
- Contracted with four local sites to undertake prevention activities (ME, NY, CA and WA)
- Conducted conference call with Advisory Committee members and site coordinators
- Held Advisory Committee Meeting, September 11, 2002, in conjunction with LDA-MA Annual Conference
- Contracted with web designer with projected launch date of Healthychildrenproject.org being June 1, 2003
- Drafted HCP announcement postcard – logo design imminent
- Continually gather names of local community organizations from local sites for database
- Gather informational material for distribution to local sites
- Published article in November/December issue of *Newsbriefs* describing the creation, purpose and goals of the Healthy Children Project
- Working on grant template for local sites
- Joined with other environmental groups in partnership working together on environmental issues significant to the development of children: Beyond Pesticides, Center for Health, Environment and Justice, Children's Environmental Health Network, Children's Health Environmental Coalition, Clean Water Action, Commonwealth – Collaborative on Health and the Environment, Internet Initiative on Children's Health and the Environment, Pollution Probe, Canadian Association of Physicians for the Environment, West Harlem Environmental Action Inc., Women's Voices for the Earth, and others
- Sent materials to General Federation of Women's Clubs (6,000 member groups) for review for their own dissemination.
- Contacted LDA affiliates and their sister State PIRG offices urging collaboration at a local level – initially, by underwriting a op-ed piece jointly composed by Jane Browning, LDA Executive Director, and Jeremiah Baumann, Environmental Health Advocate, US Public Interest Research Group, calling for common-sense prevention of the impact of toxins and chemicals on the health of our children by way of health tracking network.
- Seven more state affiliates signed up to participate in the Healthy Children Project after the LDA's annual international conference held in Chicago in February, 2003.

LDA New York

- Mike Helman, President of LDA New York, spoke at a joint press conference with NYPIRG responding to CDC's report on Human Exposure to Environmental Chemicals on Monday, February 3, 2003. His basic message was that the effects of chemicals in our

bodies are a huge problem, and what we know about the 120 chemicals in the report is a cause for great concern. Biomonitoring is an important tool to track not only those chemicals but the vast amount of other toxins to which we are exposed daily. He made the correlation between outdated toxic regulations and the danger we face from these preventable exposures.

- Mike met with the Attorney General of New York in late fall and has since been working with other environmental organizations that participated in that meeting on key pieces of legislation surrounding the use of pesticides
- Collaboration between LDA-NY with other environmental organizations and cancer groups to pursue the refinancing of their State's Superfund
- Working with NYPIRG (Public Interest Research Group) on a report that indicates population exposure to toxic sites by zip code.

LDA-Maine

- Was significantly instrumental in the passage of two bills by the Maine legislature reducing the amount of mercury allowed in Maine's environment
- Received a \$10,500 grant from the John Merck Fund to work collaboratively with other advocacy groups on environmental health policy issues.
- LDA-ME is poised to take on the challenge of dioxin in their state's water supply - dioxin is a toxic byproduct of the paper mills
- LDA-ME has joined with seven other health professional and environmentalist groups which fight against harmful toxins to form The Alliance for a Clean and Healthy Maine, which collectively represents some 25,000 Maine members.

LDA-WA

- LDA of Washington continues to work collaboratively with the Institute for Children's Environmental Health in pursuing their efforts to develop a youth focused and driven program in the State of Washington. They are utilizing the talents of a specialized volunteer who works exclusively in organizing and working with the youth who will use their creativity in raising public awareness to the dangers of environmental toxins in their schools, homes and communities.
- LDA-WA Board of Directors has passed a policy resolution to support HB #1002 which moves to reduce and eliminate mercury use and production in Washington.

LDA-CA

- Recent LDA-CA activities regarding children's environmental health include arriving at consensus to give high priority to research, tracking, prevention, and education via implementation of their new 2003 Strategic Plan.
- LDA-CA joined the Collaborative on Health and the Environment (CHE), a network of over 300 organizations and individuals throughout the country including health-affected patient/client/student groups, physicians, nurses, scientists, and environmental health advocates. LDA-CA leaders will contribute to CHE projects and disseminate research and other health information thorough state and local affiliate publications.
- At the January 25 Executive Committee meeting discussion was focused on endorsement of a bill by Wilma Chan, a partner with CalPIRG, to support ban of PBDE's in

California. PBDE's are Polybrominated Diphenyl Ethers and if the bill is passed CA may be only the 1st or 2nd state to introduce legislation to ban them. They are used as flame retardants in computer plastics, polyurethane foam products, and commercial textiles.

- LDA-CA past president, Jo Behm, RN, testified before the California legislature last fall and will continue to partner with other CHE organizations to bring about legislation to minimize or eliminate risks of toxic exposure and harm to children, pregnant women, and developing fetuses.
- Six members of LDA-CA from throughout the state participated in a precedent setting California IDEA Reauthorization Summit on January 18, 2003.

American Association on Mental Retardation (AAMR)

– Doreen Croser, Executive Director

Doreen gave an overview of the conference AAMR will hold at the Wingspread Conference Center in July, 2003, entitled, *Collaborating For Action: A National Invitational Summit To Reduce the Unnecessary Occurrence of Mental Retardation Caused by Environmental Pollutants and Toxins*

Doreen first described the need for a National Invitational Summit:

The evidence is mounting that exposure to environmental pollutants and toxins is contributing to poorer health and significant increases in chronic disease and disabilities in our society. Mental retardation is indeed costly in human and economic terms and while AAMR firmly believes that dignity, service and support must be afforded to every individual who has this disability in our society, we also strongly support preventing unnecessary disabilities from occurring in the first place.

Unfortunately, in recent years, disability prevention and health promotion activities have not been a high priority among the national mental retardation associations and organizations. More attention has been given to improving the quality of community service programs, supporting the growth of the self-advocacy movement, and eliminating long waiting lists for adult services. Although these issues are important, in view of the intensifying societal interest in environmental issues, increasing scientific knowledge, the growing sophistication and advocacy strength of the broader health and environment community network, and the increasing awareness about how to educate people about preventing unnecessary disabilities from occurring, the time is right to reenergize the mental retardation network. Organizations concerned about mental retardation must put disability prevention and health promotion back on their priority agenda and AAMR proposes to lead that effort beginning with a National Invitational Summit.

In this context, it is important to acknowledge that prevention is a very sensitive issue in the mental retardation field. Primary prevention activities can be controversial, especially among people with mental retardation and their advocates who may hold the view that prevention activities are offensive because they diminish the inherent worth and human value of the individual in our society who has that disability. That said, we feel that choosing to prevent unnecessary disabilities from occurring does not devalue those who have this disability but

simply affirms our interest in contributing to a better quality of life for current and future generations.

Doreen then described the Summit Purpose and Objectives:

With a long and distinguished 126 year history that includes international credibility in research, education, and policy, coupled with a membership comprised of national health and disability leaders, AAMR proposes to convene an intensive, invitational Action Planning Summit. The goal of the Summit will be to create a National Blueprint for Health Promotion and Disability Prevention that will contribute to the broader national effort aimed at reducing the unnecessary occurrence of disabilities due to avoidable exposure to pollutants and toxins.

The National Blueprint will be developed by inviting health and environmental experts to collaborate with disability leaders in the field of mental retardation, as well as parents and individuals with disabilities, to address several key questions:

- What do we know about toxins that affect brain development such as lead, mercury, alcohol, nicotine, pesticides, PCB's, solvents, etc?
- What is known about the relationship between these toxins and the occurrence of mental retardation and related developmental disabilities?
- What can be done to prevent the unnecessary causes of mental retardation and related developmental disabilities?
- What innovative efforts are currently being taken across the country in the areas of research, service and public policy?
- What is the impact of environmental toxins on the functional abilities of people in our society who are living with mental retardation?
- What specific action steps can be taken by the national MRDD organizations to educate and mobilize our constituencies in support of the National Blueprint to prevent the unnecessary occurrence of mental retardation?
- How can we deliver a compelling health promotion and disability prevention message to our constituency?

The specific objectives of the invitational Action Planning Summit include:

- To provide accurate data that will provide a common framework for the collaborating partners including the current state-of-the-art in scientific research, innovative health education and prevention efforts, and cutting-edge state and national policy initiatives.
- To establish collaborative relationships between the environmental health community and the mental retardation disability network by identifying issues of mutual concern and areas for collaborative action.
- To create a vision that will guide development of a National Blueprint on Health Promotion and Disability Prevention for the mental retardation network.

- To develop a Broad Consensus Statement that the MRDD groups can endorse.
- To frame a National Blueprint for the disability organizations that will:
 - Articulate important research findings.
 - Identify areas where future research can be supported.
 - Highlight innovative service initiatives.
 - Recommend state and national policy directions.
 - Develop a common message for health promotion and disability prevention.
 - Articulate communication strategies for participating stakeholders.
 - Identify an expanded network of partners.
 - Articulate next steps in implementing the National Blueprint (including media and policy opportunities).

In addition to the Summit, Doreen also mentioned that AAMR had recently written a letter to Andrew J. Spano, Westchester County Executive, regarding the establishment of a “No Pesticides Day” in that county.

1) Initiatives of other groups and additional suggestions:

- Clean Water Action – “Home Safe Home” guide on using least toxic products in the home.
- The Arc – the CDC is funding four groups on neurodevelopmental research and the focus is on services. For example, looking at whether a higher proportion of kids in foster care exhibit developmental delays.
- Other Autism groups we might engage:
 - Defeat Autism Now (primarily a group of physicians affiliated with the American Academy of Environmental Medicine)
 - Safe Minds (Liz Bert)
 - Autism Network for Dietary Therapies
 - American Speech and Hearing Association
- Other LDD groups we might engage:
 - National Association on Dual Diagnoses
 - CHADD
 - Interagency Commission for Disability Research
- Create a central database for LDDI of all the organizations and what they focus on so that we have a map of this sector (Jo Behm). The group agreed this would be useful. Elise suggested that this would be like what she did with the children’s environmental health field, and that if she did it for LDDI, she would need to have others in LDDI working on this with her.
- Establish a “googlenews”-style internet feature that would allow all of us to keep up with each other’s initiatives, reports and efforts more effectively and efficiently (Pete Myers). Given the huge numbers of groups working in this area as well as the scientific and educational materials that are being produced daily, it is extremely difficult to keep up with everyone and cross-pollinate. By working with the web masters of each organization, we could automatically link to each organization’s website and be informed about new information being disseminated. The group agreed this could be a great idea,

and Pete requested that organizations with an interest in experimenting with this be in touch with him. Marc Dubin said that he is doing something similar with his cavnet.org web site and that he and Pete should confer.

Review of LDDI Draft Resolution

Elise reminded the group that the LDDI Resolution was to be used both as a way to leverage other LDD organizations to join us as well as to leverage policies related to the hazardous environmental exposures that may impact brain development. People can sign on either individually as well as organizationally (knowing that in some organizations, a resolution like this would need to be passed by the board or go through some other process), but that the Resolution would carry more weight if organizations signed on. Elise also noted that by signing on the Resolution does not mean that an organization endorses a particular bill—it is simply an indication that we share common concerns and recommend particular actions to address those concerns.

Some suggested that individual organizations might “tweak” the Resolution for their specific efforts. This seemed fine in a general context but that every organization would have to agree with the wording of the basic resolution (i.e., we can’t have 15 slightly different resolutions because that defeats the purpose) even if it isn’t “perfect” or address everything just as their organization might.

The group then gave specific feedback, including adding a letter of some kind that would provide an overview of LDDI, members and contact information. Elise said she would incorporate the suggestions and edits made and recirculate with the intention of finalizing a resolution by mid-April.

Review Of LDDI Fact Sheet Based on CDC “Biomonitoring” Report

Though the group decided that having this fact sheet would be a critical tool to raise public awareness, and Elise said she would work with Arnie Wendroff, who did the first draft, and others to finalize this.

Media Opportunities

Amy Kostant noted that some opportunities right now include a press event with the LDA on thyroid as well as a focus on safe homes, safe schools and flame retardants. She also said it is challenging to get articles in parenting magazines until there is enough press on a certain subject, like mercury thermometers, in mainstream newspapers, etc.

She emphasized that she wants to work with LDD groups in whatever ways might be useful, and in order to do this, she would greatly appreciate information on “myths vs. facts” regarding

neurotoxicants and LDDs, for example, on mercury in vaccines and their possible connection to autism.

Amy then asked if there were any “natural enemies” of the LDD groups. Jane Browning mentioned that the Church of Scientology does not see LDDs as anything to identify, provide services for, or prevent. Other thoughts included insurance companies, state governments, the Department of Labor, all of which are not necessarily supportive of identifying those with LDDs because of the additional costs.

Additional ideas:

- Raise awareness in media about child abuse and domestic violence and how these may be connected to or exacerbated by hazardous environmental exposures. Marc Dubin suggested that along these lines, he intends to establish awards for police, judges, prosecutors and others who are sensitive to these concerns.
- Electronic waste (with the many neurotoxicants in this waste) may be a good focal point. Apple Computers has just established a take back policy and Al Gore has just joined Apple’s board. May be a great opportunity to leverage this issue.
- Put together packages for reporters perhaps every two months that would show links between neurotoxicants and LDDs.
- Need to start weaving the thread of the link between environmental exposures and unhealthy brain development in all our messaging and work.

Policy Opportunities

Jeremiah Baumann said that the State PIRGs, in regards to environmental health issues, have been focusing on:

- Right-to-know
- Health impacts of specific chemicals (ex. Flame retardants)
- Phasing out chemicals (if a company hasn’t done proper testing, it shouldn’t be on the market)
- Health tracking

He noted that you can go after the bad actors one product at a time or go after the core of the problem, such as what the European Union is doing in changing assumptions and burden of proof back on the manufacturers. Both approaches are necessary and useful right now, particularly since it is unlikely the U.S. will follow the E.U. anytime soon.

Jeremiah also emphasized that media strategies are key in states. In regards to working with LDD groups, he is happy to help develop regional op-eds, train people to do outreach to the media and communities on specific concerns, develop specific talking points, identify people within local chapters to speak to issues, and help highlight human interest stories that would attract media attention.

Criminal Justice Task Force

Elise reminded people to look at the information regarding the goals and mission of the new LDDI Criminal Justice Task Force as defined in February 2003:

The Learning and other Developmental Disabilities Initiative has launched a sub work group, the Criminal Justice Task Force, to examine whether environmental contaminants, which are recognized as risk factors for learning and developmental disabilities (LDDs), may also be risk factors for those LDDs known to be characteristic of a disproportionate number of those who end up in the juvenile and criminal justice system as perpetrators or victims.

Simply put, if environmental contaminants contribute to LDDs, and if these LDDs put youth at increased risk of ending up in the juvenile and criminal justice system, then should not fetal and early childhood exposure to these contaminants be considered a risk factor propensity to asocial behaviors?

Recognizing the significant role that poverty and racial factors are known to play in the criminal justice system, the Task Force recognizes the need to assess the possible contribution of environmental contaminants in the framework of these and other established risk factors. The fact that low income communities and communities of color are often exposed to higher levels of environmental contamination may therefore place them at additional risk for juvenile delinquency or criminal behavior.

In relation to these issues, the three primary goals of the Task Force are:

1. To identify resources and research on the relationship between environmental contaminants, cognitive and related developmental disabilities, and criminal behavior.
2. To stimulate dialogue on these issues, and to broaden the constituencies engaged in this discourse.
3. To consider, based on assessment of the evidence, what the implications are for public policy.

The Task Force organizers are Jane Browning, Executive Director of LDA and Ron Hume, Director of Affiliate Services, LDA. Task Force members are Michael Lerner, Commonwealth Institute; Elise Miller, Institute for Children's Environmental Health; and Ted Schettler, Science and Environmental Health Network. Invited to participate but not yet confirmed are Doreen Croser, Executive Director of AAMR and Ruth Luckasson, President of AAMR.

The primary focus of the Task Force needs to be determining what we know, creating a central database for this information, and figuring out who else should join the task force.

Marc Dubin said he would work with Jane Browning to create a place to collect data on the links between environmental exposures and criminal justice.

Several people and organizations who might be helpful allies were suggested.

- Sheryl Dicker, JD, Executive Director, State of New York Permanent Judicial Commission on Justice for Children. (914) 948-7570 sdicker@courts.state.ny.us
- Dr. Dimitri Papplos, of the Juvenile Bipolar Research Foundation at www.jbrf.org
- National Association of Women Judges
- Violence Research Association
- National Institute for Juvenile Justice

Action Steps for LDDI

- Finalize the LDDI Resolution.
- Finalize the fact sheet for LDD groups based on the CDC biomonitoring report.
- Create central database.
- Create media fact sheets on “myths vs. facts.”
- Continue to share information and scientific articles.
- Engage the suggested organizations regarding LDDI.
- Determine specific media and policy opportunities LDDI could collectively focus on.

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