

LEARNING AND DEVELOPMENTAL DISABILITIES INITIATIVE (LDDI)
-- a working group of the national Collaborative on Health and the Environment
Quarterly Conference Call

Notes

June 20, 2006

****NEXT LDDI CALL: Monday, September 11th at 2:00 p.m. Eastern****

Participants:

- Steve Boese, Healthy Schools Network
- Kathy Burns, ScienceCorps
- Kitty Christiansen, Learning Disabilities Association of Minnesota
- Tina Cosentino, Pesticide Action Network
- Kate Davies, Antioch University Seattle
- Sharon Davis, The Arc
- Neil Gendel, Healthy Children Organizing Project, Consumer Action
- Lynne Heilbrun, University of Texas Health Science Center at San Antonio
- Ruth Hennig, John Merck Fund
- Ginger Johnson, Learning Disabilities Association of Missouri
- Amy Kostant, Environmental Media Services
- Kathy Lawson, Learning Disabilities Association of American/Healthy Children Project
- Heather Loukmas, Learning Disabilities Association of New York State
- Elise Miller, Institute for Children's Environmental Health and national chair of LDDI
- Ted Schettler, Science and Environmental Health Network
- Theodora Tsongas, Oregon Public Health, Department of Human Services
- Michele Wagner, American Association on Mental Retardation (*soon to be renamed the American Association for Intellectual and Developmental Disabilities*)
- Amy Winans, Association for Children's Mental Health

NOTES

1) Presentations by coordinators of the three new LDDI state-based initiatives

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

Heather first noted that to help develop LDDI-NY she is working closely with the Alliance for a Toxic-Free Future (ATFF), which is a statewide alliance of diverse organizations working on environmental health issues. ATFF has six different task forces of the alliance, and she co-sponsors Children's Environmental Health (CEH) Task Force with Healthy Schools Network of New York. The first half of 2006 has been spent on policy-related initiatives since the New York State legislature is only in session from January to June. She then gave a brief overview of the legislative priorities of CEH Task Force for 2006:

- Advocated to ban lindane. This did not pass due to opposition from medical professionals, but they will continue to try to get this through and will share "lessons learned" with other states trying to do similar bans.

- Still working to establish a Children's Environmental Health & Safety Advisory Council, which would submit reports to the legislature on needed regulations to protect and improve children's environmental health. The Council would also make recommendations to impacted state agencies.
- Successfully advocated for seed funding for a statewide network of Children's Environmental Health Centers of Excellence that would diagnose and treat environmental diseases, train physicians and do community outreach.
- Currently working on a lead in jewelry bill. The CEH Task Force originally supported the bill but changes were made that now make the bill extremely weak. Task Force is now working to stop the bill from passing.
- Engaged in advocacy related to the development of regulations implementing our state's green cleaning in schools law.

Heather then mentioned that the CEH Task Force organized its own Advocacy Day in March 2006 in which we shared information about the above-indicated efforts. The full ATFF had advocacy day in May 2006 in which we talked about the ATFF in general and the overall policy priorities for the ATFF.

Heather noted other activities, which included two days of public outreach in the state capital to other organizations and the public on the ATFF and environmental health issues. The first event included many teachers, who were all interested in information on the link between environmental toxins and learning and developmental disabilities. The second event was at Legislative Disabilities Awareness Day. Heather spoke to many other organizations working in the learning and developmental disabilities field on the issues and the ATFF. Specific ones that she plans to have follow-up meetings with include the New York State Brain Injury Association, Epilepsy Association of New York State and the Self-Advocacy Association of New York State.

As part of the LDDI work, she has also been working to recruit providers of mental health services to the ATFF, including the Mental Health Association of New York State and the Families Together in New York State, which provides advocacy and services to children with mental health disorders. In addition, Heather has been developing a database of potential organizational participants in the ATFF comprised of medical professionals and public health organizations. Successful additional recent recruitments to ATFF, include the New York State ARC, Inc. (NYSARC, largest nonprofit in U.S. providing services to individuals with developmental disabilities), the New York State Developmental Disabilities Planning Council (DDPC), and seven regional Learning Disabilities Associations (LDAs).

Other outreach work includes organizing a meeting with developmental disabilities providers. Heather will be working with NYSARC and DDPC to plan a one-day informational meeting for providers of services to individuals with developmental disabilities to come and listen to the science related to environmental toxins and developmental disabilities and will then talk to them about the ATFF and how they can get involved. She will also be serving on a committee to begin developing a plan to pursue statewide chemicals policy change. ATFF will hold a retreat in September to

focus on this issue. In addition, she will help plan a series of community-based outreach events through our regional LDA affiliates.

b) Amy Winans, Executive Director, Association for Children's Mental Health and coordinator of the Learning Disabilities Association of Michigan's (LDA of MI's) Healthy Children Project

Amy noted that as part of the LDDI efforts in Michigan, she has helped launch the LDA of Michigan's Health Children Project monthly e-Newsletter in January 2006. So far six editions have been published. Its purpose is to summarize the most pertinent, current information about environmental factors that impact developing fetuses, the newborn or young children and the actions we can take to minimize or eliminate those factors. To view a copy, go to <http://www.ldaofmichigan.org/healthychildnews.htm>. Or to subscribe, simply send a blank email message to healthychildrenproject-subscribe@yahoogroups.com. She noted they have already gotten very positive feedback on these.

To augment LDDI-MI work, the LDA of MI has joined as a member of the newly formed Michigan Network for Children's Environmental Health (MNCEH). It is a network of health professional and environmental organizations (including the American Academy of Pediatrics-Michigan Chapter, the Ecology Center, and other groups and individuals dedicated to a safe and less-toxic world for Michigan's children. MNCEH plans to work to change current policies and practices that result in exposure of children to environmental toxicants through education, outreach, and advocacy. MNCEH has applied for a grant through the Beldon Fund, and their first campaign is to support legislation which will ban the use of lindane. She will look to Heather for ideas in regards to what worked and didn't in New York State along these lines. (Kathy Burns also mentioned that there are some good analyses in California looking at the economic costs of exposures to pesticides like lindane). A campaign on mercury concerns is also in the making.

LDA of MI is also near completion of a guide for families – a document providing tips on safe and less-toxic practices for families (this guide is modeled from one published by LDA of Maine). She said they plan to continue to have related articles in their newsletter, *Outlook*, and they will be hosting a session on environmental health at the LDA of MI annual conference.

c) Kitty Christiansen, Executive Director, Learning Disabilities Association of Minnesota (LDA of MN)

Kitty first mentioned that LDDI efforts in Minnesota in many ways started last fall when she and Kathleen Schuler from the Institute for Agriculture and Trade Policy (IATP) co-presented on neurotoxicants and learning and developmental disabilities at a conference at the University of Minnesota. She then got involved in helping to plan the LDDI-Minnesota conference, which was entitled "Preventing Harm to Growing Brains" and held January 21, 2006, in Minneapolis.

Subsequent to the conference, she participated in the first follow-up meeting in February to determine what priorities group members would like to focus on. There were 34

attendees representing diverse organizations such as The Arc-Greater Twin Cities, Clean Water Action, Roseville schools, Environmental Justice Advocacy of Minnesota and Minnesota Department of Agriculture. Local initiatives were identified including Minneapolis Park & Recreation Board's proposed "Organic Land Care Initiative" and efforts to get the Minneapolis city government to adopt policies for nontoxic cleaning products. Participants were encouraged to join CHE's LDDI and attendees' names were added to IATP's Children's Environmental Health listserv. Other interests that were expressed at the meeting were healthy schools, curriculum development on environmental health, mercury and pesticides. Work groups will convene to further efforts on these issues.

Kitty said that the next follow-up meeting held in March focused on the need for research on the health costs of ADHD and learning disabilities related to environmental exposures and plans to distribute legislative action alerts to membership regarding mercury.

The third follow-up meeting was held in April. Attendees included parents, teachers, and representatives from Minnesota Department of Human Services, Ramsey City Environmental Health, Women's Environmental Institute and the Minnesota Office of Environmental Action-Pollution Control Agency. Presentations were made on 1) the Mercury-Free Minnesota campaign – mercury reduction from coal plant emissions bill passed (90% reductions by 2014 – ahead of EPA rules, which is 70% reduction by 2018) and included a utilities requirement to inform consumers of waste disposal sites for fluorescent bulbs, which contain mercury; and 2) Getting Mercury Out of All Vaccines initiative, but that legislation did not pass. At the meeting, there was also a report on healthy schools effort, with the initial focus – safe drinking water in schools (resolution to be adopted by Minnesota Public Health Association).

Kitty then mentioned that she is now part of the new Chemical Policy Reform Steering Committee in Minnesota, lead by IATP and Minnesota Clean Water Action. Members include those two groups as well as The Arc of MN, LDA of MN, Environmental Justice Advocates of Minnesota, Women's Environmental Institute and the Minnesota Nurses Association. With outside facilitator, the Steering Committee:

- Learned about chemical policy initiatives in Minnesota and other states
- Identified that the purpose of the new campaign was a focus on public health, rather than a chemical-by-chemical approach to legislation
- Discussed the structure of the steering committee – Developed ground rules and norms, roles, group process, decision making, work plans, elements and outcomes of a first-year campaign
- Set up a series of meetings through the summer and next steps

They also defined intended outcomes:

- Establish coalition and campaign structure
- Distribute Beldon grant funds appropriately
- Develop messaging and communications strategy
- Determine strategic plan and campaign name
- Develop plans for outreach and organizing of other coalition member agencies
- Undertake policy research and development

- Develop legislative agenda by December
- Develop marketing strategies
- Work to create more civic engagement

2) Updates on recent events and other current efforts:

- a) Autism Society of America (ASA) – Elise mentioned that ASA has created an advisory group on their new environmental health initiative and she serves on that. They have been meeting by phone every couple of weeks in addition to subcommittee calls on specific projects. As part of this effort, Elise, Martha Herbert and Joan Cranmer are serving as guest editors for an issue of ASA’s publication “The Advocate,” which will focus exclusively on environmental health. In addition, Elise organized a LDDI panel for ASA’s national conference in July in Providence, RI.

- b) Autism Strategy Group – This group emerged out of a meeting at Commonweal last fall and is now planning a CME course conference, “Clinical Implications of Environmental Toxicology for Children’s Neurodevelopment in Autism”, which will take place at the MIND Institute at UC Davis in Sacramento. Speakers will review the state of scientific discourse on new developments in autism research and medical treatments, and Elise will present on LDDI. This will be followed by a smaller Commonweal conference, “New Paradigms in Autism Research & Treatment (NPART).” This meeting will be an opportunity for a unique group of leaders in the national autism community to discuss these new developments in research and clinical practice in a balanced and collegial environment.

- c) American Association on Mental Retardation – Michele Wagner mentioned that among many other activities, including a number of speaking engagements, recent publications, etc., she is now preparing for their Fall 2006 Teleconference Series with lectures on environmental contributors to developmental disabilities. Some of the fall lecturers will be Leo Trasande on mercury, Ted Slotkin on environmental tobacco smoke, Barb Sattler on environmental health for nurses working with those with learning disabilities, and Mark Opler on lead exposure and schizophrenia, who also spoke on the spring 2006 LDDI call.

- d) Learning Disabilities Association of America – Kathy Lawson mentioned the Healthy Children Project has been very busy, particularly with activities in Pittsburgh, and she, Ginger Johnson and Elise are discussing a possible LDDI meeting in Missouri in the fall 2006 or spring 2007.

- e) Healthy Schools Network – Steve Boese, following up on what Heather Loukmas presented, talked about the Children’s Environmental Health (CEH) Partnership, which is a partnership between LDA of NYS and the Healthy Schools Network funded by the Robert Sterling Clark Foundation. They provide regular communication on CEH issues to key policymakers through monthly newsletter. They will also be releasing a white paper on the current regulatory status of CEH in New York State by the end of summer. In addition, they are planning a

Leadership Symposium on Children's Environmental Health for Fall 2006. The symposium will be geared toward key policymakers in New York State.

- f) Parkinson's Working Group – Elise said that she has been engaged with the CHE Parkinson's Working Group as LDDI looks to include both neurodevelopmental and neurodegenerative diseases. She is helping to plan a major conference on environmental contributors to Parkinson's that will likely be held early spring 2007. This conference will produce a consensus statement, similar to the one that the CHE Infertility Working Group did.
- g) LDDI's Resolution – Speaking of consensus statements, Elise said she would like to revisit LDDI's original "Resolution," drafted over three years ago, and redraft it as a consensus statement that would mirror the consensus statements already posted on the CHE national website for other health concerns. If there is anyone interested in working on that, she would welcome help with that.
- h) LDDI legislative database – Elise reminded the group that we are continuing to work to add states to the legislative database and welcome input from LDDI members as to legislation as well as organizations in each state working on environmental health issues related to neurotoxicants.
- i) Practice Prevention columns – Elise also reminded the group that the latest Practice Prevention column is on plastics and is available on the LDDI web site (www.iceh.org/LDDI.html). ICEH staff are now translating that into Spanish and updating other columns.
- j) International Mercury Conference – Kathy Burns mentioned that people might be interested in attending the International Conference on Mercury as a Global Pollutant to be held August 6 - 11, 2006 in Madison, Wisconsin. Website: www.mercury2006.org/Default.aspx?tabid=1435

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