

LEARNING AND DEVELOPMENTAL DISABILITIES INITIATIVE

MEETING NOTES

May 23, 2002

9:30 a.m. to 2:00 p.m.

The City Club, Washington, DC

Participants

Jane Browning, Executive Director, Learning Disabilities Association of America

Sandra Cort, Vice President, Learning Disabilities Association of Maine

Doreen Croser, Executive Director, American Association on Mental Retardation

Sharon Davis, Director of Professional and Family Services, Association of Retarded Citizens

Frank Hatch, Chair, Board of Directors, John Merck Fund

Ruth Hennig, Executive Director, John Merck Fund

Elise Miller, Executive Director, Institute for Children's Environmental Health and National Coordinator for the Collaborative on Health and the Environment's Learning and Developmental Disability Initiative

Brian Rasmussen, Senior Policy Advisor, United Cerebral Palsy Association

Ted Schettler, MD, MPH, Science Director, Science and Environmental Health Network and Greater Boston Physicians for Social Responsibility

Nichelle Schoultz, Grassroots Coordinator, Epilepsy Foundation of America

Larry Silver, MD, Recent Past President, Learning Disabilities Association of America

Welcome

Elise Miller welcomed everyone, thanked Jane Browning for reserving the venue and food for our meeting as well as Frank Hatch and Ruth Hennig for The John Merck Fund's support and interest. Participants then introduced themselves.

Next Elise gave an overview of the inception and mission of the Collaborative on Health and the Environment (CHE) and how the Learning and Developmental Disabilities Initiative (LDDI) fits into CHE's national efforts. She referred everyone to the packets for more detailed information on CHE, including the consensus statement.

Brief Overview of Participating Organizations

Elise asked all the learning and developmental disabilities groups to briefly describe their organizations and any particular projects they have done related to environmental exposures and neurological development as well as their interest level in this area.

1) American Association on Mental Retardation (AAMR):

Doreen Croser described the 126-year-old institution and its mission to “promote progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities.” She mentioned that AAMR has over 9,500 members in the U.S. and hundreds of other members in 55 other countries. Doreen also said that AAMR published a book on toxic substances in relation to mental retardation about 20 years ago, and though environmental health per se has not been a program priority, AAMR has a standing committee on health promotion and prevention which might want to focus more on toxic environmental exposures. She said she would be very interested in getting more involved with this effort.

2) United Cerebral Palsy Association (UCP):

Brian Rasmussen mentioned that UCP has 111 affiliates in 39 states. The national office provides referral services for affiliates and also serves people with disabilities through various programs, legislative advocacy, technology initiatives and research. USP has not focused on environmental exposures per se, but in the legislative realm, two major areas USP is pushing include: a) increased appropriation for new research; and b) health tracking legislation. Brian said he is currently working with Congresswoman Nancy Pelosi and Sen. Hillary Clinton on the new Health Tracking Act 2002. For now, he said this may be the main point of connection with LDDI.

3) Learning Disabilities Association of Maine (LDA of ME):

Sandy Cort described her long-standing concerns both about the environment and learning disabilities. She then spoke of her recent efforts, as Vice President of the LDA of ME, with the Natural Resources Council of Maine and other advocacy organizations to help pass legislation to phase out mercury in Maine. She sees the two model bills, “An Act to Phase Out Availability of Mercury-added Products” and “An Act to Prevent Mercury Emissions when Recycling and Disposing of Motor Vehicles” that eliminate mercury pollution, are a first step towards reducing neurotoxins that can contribute to developmental problems. She sees many more opportunities for the LDA of ME to collaborate on other policy and legislative actions, such as paper mill dioxin, to further eliminate other toxic environmental exposures that may contribute to learning and developmental disabilities.

4) Learning Disabilities Association of America (LDA):

Jane Browning described LDA's dedication to identifying causes and promoting prevention of learning disabilities and to enhancing the quality of life for those with learning disabilities and their families. LDA currently has 50 state affiliates and more than 450 local chapters in all 50 states, Washington, DC and Puerto Rico. Current membership totals more than 40,000. Jane said that LDA is very committed to working collaboratively to eliminate environmental exposures that may lead to learning disabilities. The LDA sent out copies of the Greater Boston's Physicians for Social Responsibility's "In Harm's Way: Toxic Threat's to Child Development" report to all the heads of the state chapters. The LDA is now envisioning a new initiative, The Healthy Children Project, which is focused on bridging the gap between research and practice regarding environmental health links to neurological problems. The goal is to heighten the awareness among our constituencies, including parents of young children, women who wish to become pregnant or are pregnant, and health care professionals who regularly interact with them. This is a preventative effort to create informed consumers who can advocate for preventative strategies and ensure that their health and the health of their offspring is not compromised. As part of The Healthy Child Project, the LDA will also work with a few key state affiliates where there is particular interest in environmental links to learning disabilities. This will include educational outreach and possible advocacy actions in those states.

5) The Epilepsy Foundation of America (EFA):

Nichelle Schultz said EFA was founded in 1968 and is the only such organization wholly dedicated to the welfare of people with epilepsy. EFA's mission is to work for children and adults affected by seizures through research, education, advocacy and service. Nichelle mentioned that EFA has not focused at all on environmental concerns, and primarily is interested in increased research on new therapies for seizures and ensuring access to care. When she did a web search on any publications pertaining to environmental links to epilepsy, she found very little. That said, she said she was very interested in pursuing this issue, and will bring back information from this meeting to her colleagues and determine what steps EFA might want to take. She said "even if this is just educational, it seems really important we know about this work [on environmental exposures]."

6) The Association for Retarded Citizens of the United States (ARC):

Sharon Davis said the ARC has 140,000 members. ARC serves people with cognitive, intellectual and developmental disabilities, and no longer use the term "mental retardation." She also mentioned that they know the causes for about 50% of these disabilities, but not the rest, and says that in her mind environment could be a factor. ARC generally funds research directly and has not been focused on primary prevention, but they do now provide fact sheets on fetal-alcohol syndrome, lead and endocrine disrupters in relation to neurological development. In New Jersey, ARC participates on the Governor's Council on Prevention of Disabilities and has developed a handbook.

Sharon also said that she is interested in environmental contributors, but feels there needs to be more solid science in order for ARC to take any specific actions at this time.

The John Merck Fund

Frank Hatch gave a brief history of The John Merck Fund (JMF) and why JMF is so interested in preventing developmental problems, noting that JMF has been funding neurological research almost since its inception. **Ruth Hennig** affirmed the Fund's interest and appreciation for this opportunity to work with a wide range of learning and developmental disabilities groups on educational outreach and potential advocacy.

Presentations

Ted Schettler presented on "In Harm's Way: Toxic Threats to Child Development." He distributed copies of the "In Harm's Way" report to all participants. Using hand-outs of his slides, Ted described what we currently know about environmental links to various learning and developmental disabilities. (Please see your hand-outs for detailed information.) He also underscored that though there are clearly social and genetic factors, environmental exposures are the least researched and the most preventable. In addition, as the new science emerges, he said we all need to reflect, individually and as organizational representatives: "When do we know enough to take action?"

Larry Silver presented on the clinical view of child development and neurological problems. He described the complexity of brain development and the various ways that development can go awry. He noted that one of the most difficult parts of diagnosing the problem is that development happens over fairly long periods of time, and some problems do not show up until years later. He also discussed the importance of "co-morbidity" studies because with language, learning, anxiety, or obsessive-compulsive behavior (to name a few), there is a high likelihood of having more than one of these problems.

Discussion on Further Involvement

Each group spoke to their particular interests, with some groups more poised for more immediate action than others.

LDA is most ready to take steps in terms of educating constituencies about environmental exposures and links to learning disabilities as well as taking action on specific legislation related to eliminating neurotoxicants. In addition, Jane and Larry confirmed that they will continue to work at the national level to promote these issues with other state heads and have the "medical symposium" strand each year at the national LDA meeting focused on environmental exposures, etc. and begin to make concerted efforts for a few of their state chapters, specifically in California, Washington State, Maine and western New York State. Sandy affirmed that she will continue to be very active in Maine and would very much like to provide model state initiatives that other states might replicate.

AAMR is very interested in getting more actively involved not only in educating their constituencies, but potentially on advocacy and policy levels.

ARC would like to continue to explore this opportunity, but would want to see more research on toxic exposures and mental retardation before they do much in terms of further membership education and any kind of advocacy, beyond their current efforts on lead and fetal alcohol syndrome.

UCP also would like to stay engaged and currently sees its greatest connection currently on the Health Tracking legislation.

EFA would like to find out more and would be happy to distribute information to their constituencies as appropriate. Since Nichelle works with grassroots groups, this might also be a real opportunity to do some outreach regarding environmental justice implications of these exposures.

Information Needs

All of the groups wanted more fact sheets and information they could distribute to their constituencies and information they could load on their web sites. CHE's Science Work Group could help with this. In addition, the Greater Boston Physicians for Social Responsibility already has some excellent fact sheets that could be useful. That said, we will likely need to work with participating organizations to create ones that are specific for each group, given their slightly different areas of focus or organizational structures. In addition, the LDA and AAMR underscored their interest in speakers and/or trainings on these issues.

Participants' Involvement with CHE

Elise described the possible levels of engagement with CHE, and all participants agreed to be on the CHE general listserv (which will send out no more than two e-mails a month). LDA will continue to serve on the LDDI Work Group and it may be that AAMR will also want to do that in the future.

Involving Other Organizations

We discussed how we might approach other organizations, including the Autism Society, the Asperger's Syndrome Coalition and CHADD (Children and Adults with Attention Deficit). Suggestions were made in regards to personal contacts with each of these organizations and exploring opportunities to present at their board meetings, committee meetings or other events.

In addition, we discussed engaging other 'outside the box' groups such as:

- Youth (example of "Targeting Youth" advisory council to the Governor in Maryland)
- National Federation of Women's Clubs

- League of Women Voters
- Librarians
- Rotary Clubs
- Federation of Garden Clubs

These groups may all have some interest in learning more about environmental links and have constituencies that could reach even broader audiences on these issues.

Media

The question of messaging and media outreach came up. Some groups were more eager to jump into some kind of media campaign, but all the organizations wanted to figure out how to create simple messages for their constituencies. Elise noted that there may be an opportunity to work with the Environmental Media Services on this.

Next Steps

Elise said she will send out the notes and follow up with each group by phone within the next few weeks to discuss specific opportunities and needs each organization may have. In addition, she will work with the LDDI Work Group: to determine how to do additional outreach to new groups, to distribute appropriate fact sheets and offer further trainings and educational presentations to specific groups, to develop succinct messages on LDDI and for each participating organization, and to explore media opportunities.

Meeting adjourned at 1:45 p.m.