

MIND, DISRUPTED MIND, DISRUPTED

How Toxic Chemicals May Change How We Think and Who We Are



A Biomonitoring Project with Leaders of the Learning and Developmental Disabilities Community

What would it feel like to learn your body is contaminated with toxic chemicals shown to contribute to learning and developmental effects in laboratory and human studies? Would your reaction change if your life or your child's life had been touched by a learning or developmental delay?

Twelve Americans volunteered for the *Mind, Disrupted* Biomonitoring Project to ask these questions in a very personal way: If chemicals that are all around us—in everything from baby bottles to frying pans, computers to children's toys—are also in me, could they be associated with my own learning and developmental problems? Could they be part of the reason why my children or grandchildren have disabilities? What about the children I want to have?



Sponsored by the Learning and Developmental Disabilities Initiative, whose leadership partners include: the American Association on Intellectual and Developmental Disabilities, the Autism Society, the Learning Disabilities Association of America, and the National Association for the Dually Diagnosed. With support from the Commonweal Biomonitoring Resource Center and Alaska Community Action on Toxics



Project participant Jeff Sell, of the Autism Society, with daughter Gracie, Bethesda, MD



Project participants Cathy Ficker Terrill and Beth Terrill, Chicago, IL

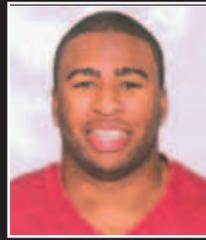
Twelve leaders and self-advocates from the learning and developmental disabilities sector volunteered to have their bodies tested for the presence of a set of chemicals that are known or suspected to be neurotoxins, hazardous to nerve cells, or endocrine disruptors with the potential to alter normal hormone function. Self-advocates are those individuals with an intellectual, learning, or developmental disability who stand up for their own rights. This is the first biomonitoring study exclusively focused on members of the learning and developmental disabilities community.

Given the current state of scientific knowledge, no one can say that an exposure to a specific chemical causes a specific developmental disability. This project does not attempt to correlate the presence or levels of chemicals with the presence, type or severity of a disability. Rather, its goal is to identify the presence of toxic chemicals that are associated with disrupting healthy neurological development in people whose lives have been directly touched by learning and developmental disabilities.

"The overwhelming evidence shows that certain environmental exposures can contribute to lifelong learning and developmental disorders. We should eliminate children's exposures to substances that we know can have these impacts by implementing stronger health-based policies requiring safer alternatives. Furthermore, we must urgently examine other environmental contaminants of concern for which safety data are lacking," explained Ted Schettler, MD, MPH, and Science Director for the Science and Environmental Health Network.

According to Phil Landrigan, MD, MSc, at the Children's Environmental Health Center at Mount Sinai School of Medicine, "We could cut the health costs of childhood disabilities and disease by billions of dollars every year by minimizing contaminants in the environment. Investing in our children's health is both cost-effective and the right thing to do."¹

DOWNLOAD THE FULL REPORT AND CHEMICAL FACTS SHEETS AT
www.minddisrupted.org



(L–R) Project participants Laura Abulafia, Stephen Boese, Maureen Swanson, David Irons, Ann WingQuest, Joseph P. Meadours

A Sampling of Participant Reactions

Project participants experienced a range of feelings and emotions after learning their bodies were contaminated with toxic chemicals including shock, anger and passion to act for change. Here is a snapshot of their reactions.

“As a father of four boys, one of whom lived a short life of overwhelming disability, I am keenly aware that prevention of learning and developmental disabilities is both an individual and a community responsibility. The enormous rise in the incidence of these disabilities is coupled with a huge increase and proliferation of chemicals in everyday consumer products. These chemicals are largely untested for human safety and largely unknown to the public.”

Stephen Boese, MSW, Executive Director of the Learning Disabilities Association of New York State; Resident of Lantham, NY

“Companies should be held accountable if they are exposing us to chemicals they know may harm us. We should know what we are being exposed to so that we can make choices to avoid exposures when we can, and we can ask government to regulate when personal exposures are difficult to avoid.”

Joseph P. Meadours, Executive Director of People First of California; learning and developmental disabilities self-advocate; Resident of Sacramento, CA

“I started going green before people really started going green. I watched what I ate and really took care of myself by using organic soaps, et cetera. I wasn’t arrogant enough to think my results would be squeaky clean, but it was a jaw-dropping moment to see my results above the 95th percentile for some of these toxic chemicals.”

Jeff Sell, Esq, Vice President of Public Policy at The Autism Society and father of two boys with Autism; Resident of Bethesda, MD

“When I was a kid in school, I tried to hide my learning disability from my friends. I hated being seen in the special education classroom. I want to know more about these chemicals that get into our bodies and how these chemicals might be hurting us and mak-



Project participant, and former Atlanta Falcon, David Irons, Atlanta, GA

ing it harder to achieve our goals. As a professional foot-ball player I have to be as mentally and physically fit as possible —it’s my job. I want to know how to avoid toxic chemicals for myself, but I also really want little kids not to be exposed to these chemicals, especially if sometimes the chemicals could harm their bodies or brains and make it harder for them to learn.”

David Irons, Professional Football Player; diagnosed with learning disability; Resident of Atlanta, GA

“Should my child be born with a serious disability or disorder, it would be a terrible responsibility wondering what I did wrong or what I could have done differently. I don’t want to live in fear that the food I eat and the products I use will impact my future children. And I shouldn’t have to. None of us should have to.”

Laura Abulafia, MHS, Director of Education and Outreach at AAIDD, and National Coordinator of LDDI; Resident of Los Angeles, CA



(L–R) Project participants Vernell Jessie, Larry B. Silver, Jeff Sell, Beth Terrill, Robert Fletcher, Cathy Ficker Terrill

Participant Body Burdens

The *Mind, Disrupted* Biomonitoring Project tested 12 people for the presence of a set of synthetic chemicals and heavy metals, including:

- bisphenol A (BPA)
- lead
- mercury
- organochlorine pesticides
- perchlorate
- perfluorinated compounds (PFCs)
- polybrominated diphenyl ethers (PBDEs)
- triclosan

Some highlights of the results:

- A total of 61 chemicals (out of 89 tested) were found in project participants.
- All 12 participants tested positive for at least 26 of the tested chemicals.
- All 12 participants had detectable levels of bisphenol A (BPA), mercury, lead, polybrominated diphenyl ethers (PBDEs), perfluorinated compounds (PFCs), perchlorate, and organochlorine pesticides in their bodies.
- 11 participants had detectable levels of triclosan.
- 6 participants had perchlorate exposure above the CDC average.
- 3 participants had lead concentrations above the CDC average.
- 10 participants had mercury levels above the CDC average.
- All 12 participants had PFOS and PFOA in their bodies.
- 8 had tested positive for PBDE 209, the brominated flame retardant known as Deca.

NOTE: Only 11 of the 12 participants chose to have their urine tested.

What's Wrong?

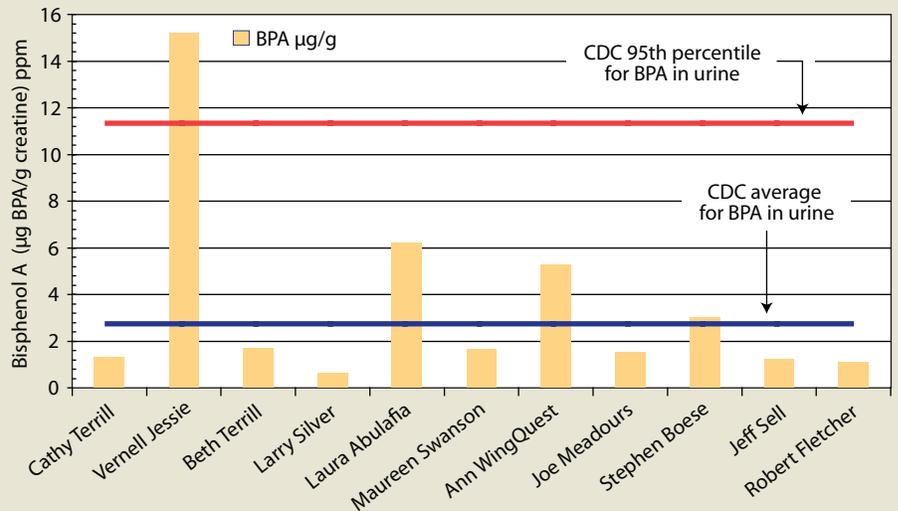
Some facts on learning and developmental disabilities in the United States:²

- According to a 1994 study, approximately 16% of U.S. children have a developmental disability,² and research shows increasing trends.³
- Between 1997 and 2006, rates of Attention Deficit and Hyperactive Disorder (ADHD) diagnosis increased an average of 3% per year.⁴ Today, approximately 4.5 million children have been diagnosed with ADHD.⁵
- The lifetime prevalence of learning disabilities in U.S. children is approximately 9.7%, according to a 2007 *Pediatrics* article.⁶
- Since the early 1990s alone, reported cases of autism spectrum disorders have increased tenfold.⁷ The United States Centers for Disease Control and Prevention (CDC) now estimates that 1 in 110 U.S. eight-year-olds have autism spectrum disorder, with an increase of 57% between 2002 and 2006.⁸

While increased awareness and improved diagnostic criteria play a role in the current figures, studies controlling for those factors imply that other culprits, such as chemical contaminants and gene-environment interactions, also likely play a role in the rising incidence of learning and developmental disabilities in the U.S.⁹

For those who already have learning or developmental disabilities, minimizing exposure to neurotoxic chemicals may mitigate the severity of their condition and improve their quality of life.¹⁰ For pregnant women, given the vulnerability of the developing fetus, minimizing exposure can mean the difference between having a healthy child or having one who is never able to reach his or her full potential and needs special services and support throughout life. Personal habits can reduce exposures but chemicals known and suspected to be neurotoxic are present in our air, water, food, consumer products, homes and workplaces—and, as this project demonstrates, also in our bodies.

Bisphenol A concentrations in Participant Urine (creatinine adjusted)

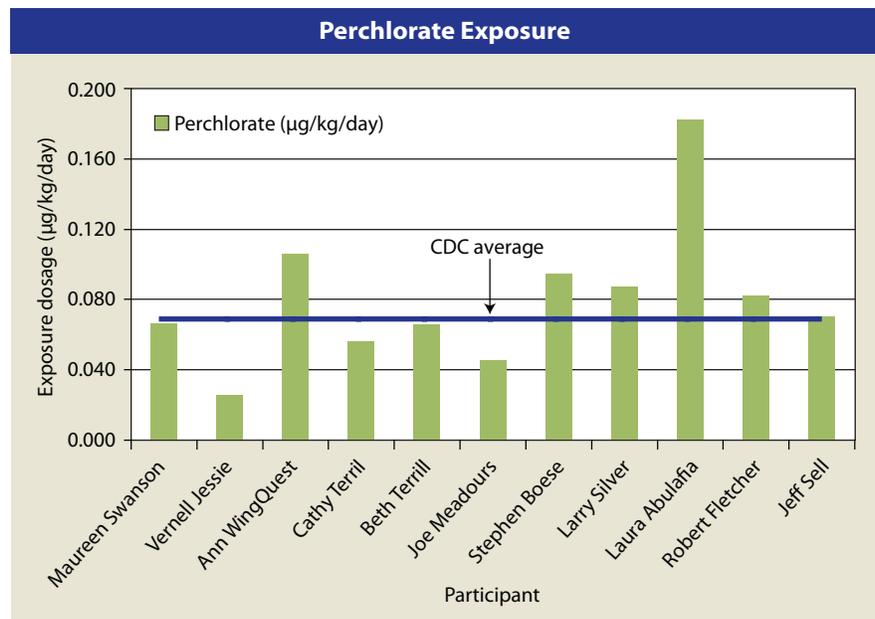


What Should Be Done Now?

Current U.S. law regulating chemicals, known as the Toxic Substances Control Act, which passed in 1976, does not adequately safeguard the public against toxic exposure. Federal policy needs to change to reflect 21st Century science—including the importance of critical windows of development, mixtures of chemicals, and low-dose exposures—to ensure current and future generations reach their fullest potential.

Federal chemicals management should be modernized to do the following:

- Take immediate action on the worst chemicals.
- Require basic information for all chemicals in the market and for those intended to be developed and marketed.
- Protect the most vulnerable from exposure.
- Use the best scientific methods.
- Hold industry responsible for demonstrating chemical safety.
- Prioritize environmental justice and protect low income, communities of color and indigenous communities that are disproportionately impacted by pollution.
- Enhance government coordination between agencies.



- Promote safer alternatives by implementing the principles of green chemistry.
- Ensure the “right to know” by requiring labeling of chemical ingredients in products.

The financial and emotional costs of learning and developmental disabilities can be overwhelming to families and communities. Early intervention therapies and special education costs can be exorbitant. Life long supports may

be required and the career and personal goals of family members may be deferred or abandoned in order to care for those affected.

Visit www.MindDisrupted.org for more details and to download the full report *Mind, Disrupted: How Toxic Chemicals May Change How We Think and Who We Are*, a biomonitoring project with leaders in the learning and developmental disabilities sector.

Endnotes

- 1 Collaborative on Health and the Environment, Learning and Developmental Disabilities Initiative (LDDI). 2008. LDDI Scientific Consensus Statement on Environmental Agents Associated with Neurodevelopmental Disorders. Available: www.healthandenvironment.org/?module=uploads&func=download&fileId=618
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