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

Nothing is at last sacred but the integrity of your own mind.
RALPH WALDO EMERSON, Essays
Sponsorship information

The Mind, Disrupted Biomonitoring Project was sponsored by the Learning and Developmental Disabilities Initiative (LDDI), whose leadership partners include: the American Association on Intellectual and Developmental Disabilities (AAIDD), the Autism Society (ASA), the Learning Disabilities Association of America (LDA), and the National Association for the Dually Diagnosed (NADD).

The Learning and Developmental Disabilities Initiative (LDDI) is a national science-based project comprised of learning and developmental disability (LDD) organizations, researchers, health professionals and environmental health groups working to address concerns about the adverse impact environmental pollutants may have on the healthy development of the brain and nervous system, and the health conditions of those who already have a learning, behavioral or developmental disorder. For more information, please see:

- www.healthandenvironment.org/working_groups/learning
- www.disabilityandenvironment.org.

The Commonweal Biomonitoring Resource Center (CBRC), www.commonweal.org, and the Alaska Community Action on Toxics (ACAT), www.akaction.org, helped to facilitate the project.

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Alaska Community Action on Toxics (ACAT)
www.akaction.org
ACAT is a statewide organization established in 1997 and dedicated to achieving environmental health and justice. The mission is to assure justice by advocating for environmental and community health. ACAT works to eliminate the production and release of harmful chemicals by industry and military sources; ensure community right-to-know; achieve policies based on the precautionary principle; and support the rights and sovereignty of Indigenous Peoples.

American Association on Intellectual and Developmental Disabilities (AAIDD)
www.aaidd.org
and AAIDD’s Environmental Health Initiative
AAIDD promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities. AAIDD launched an Environmental Health Initiative designed to promote good health and reduce disability by forging ground breaking partnerships among the developmental disabilities networks and the environmental health communities.

Autism Society
www.autism-society.org
The Autism Society increases public awareness about the day-to-day issues faced by people on the spectrum, advocates for appropriate services for individuals across the lifespan, and provides the latest information regarding treatment, education, research and advocacy.

Commonweal
www.commonweal.org
Commonweal is a nonprofit health and environmental research institute in Bolinas, California. Commonweal conducts programs that contribute to human and ecosystem health—to a safer world for people and for all life. Commonweal houses the Collaborative on Health and Environment (CHE), the Commonweal Biomonitoring Resource Center, and the Commonweal Cancer Help Program, among other programs.

Learning and Developmental Disabilities Initiative (LDDI)
www.disabilityandenvironment.org
LDDI is an international partnership fostering collaboration among learning and developmental disability organizations, researchers, health professionals and environmental health groups to address concerns about the impact environmental pollutants may have on neurological health. LDDI currently has over 400 organizational and individual participants engaged in educational and policy efforts. The LDDI site hosts an extensive list of resources on learning and developmental disabilities, including fact sheets and practice prevention columns summarizing the environmental health science for non-scientists, biomonitoring reports and peer-reviewed summaries of the scientific information regarding environmental influences on LDDs and other neurological disorders.
Learning Disabilities Association of America (LDA) and LDA’s Healthy Children’s Project

www.ldaamerica.org

LDA is the largest non-profit volunteer organization advocating for individuals with learning disabilities and has over 200 state and local affiliates. State and local affiliates work continuously for individuals with learning disabilities, their parents and the professionals who serve them. The LDA Healthy Children Project is dedicated to reducing the effects of environmental contaminants on brain development, especially in children.

National Association of Dually Diagnosed (NADD)

www.thenadd.org

NADD is a non-profit membership association established for professionals, care providers and families to promote understanding of and services for individuals who have developmental disabilities and mental health needs. The mission of NADD is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care.

Environmental Health Fund

www.environmentalhealthfund.org

The Environmental Health Fund (EHF) works to protect human health and environment from toxic and dangerous chemicals. EHF actively partners with other non-governmental organizations, governments, and visionary foundations to win chemical policy reforms, build strong networks for human health and planetary well-being, and design funding strategies that support the goal of achieving a healthier and more sustainable future free of pollutants.

Mind, Disrupted would not have been possible without leaders in the learning and developmental disability communities, environmental health communities, leading researchers and scientists, and advocates. Special thanks to Sharyle Patton from Commonweal; Laura Abulafia and Elise Miller from the Learning and Developmental Disability Initiative; Pam Miller, Sarah Petras, Colleen Keane, Sara Hannon, and Sam Byrne from Alaska Community Action on Toxics; Stephanie Hendricks; Judith Robinson from Environmental Health Fund; Elizabeth Crowe from Kentucky Environmental Foundation; Katharine Huffman and Ellie Collinson from the Raben Group; The Cedar Tree Foundation and The John Merck Fund.

A special acknowledgement is due to the participants of the Mind, Disrupted Biomonitoring Project, who made the decision to have their bodies tested for the presence of potentially neurotoxic chemicals, so that we might be reminded of the urgent need to halt further such exposures. Their dedication to this project required courage and integrity, and their time, energy, and determination to raise awareness about these pressing health concerns is greatly appreciated.

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Executive Summary

What do we know about the relationship between exposures to toxic chemicals and learning and developmental disabilities? In light of the significant increases in the incidence of autism, attention-deficit hyperactivity disorder (ADHD), and other learning and developmental disabilities, what role might environmental toxins play in undermining healthy development of the brain and nervous system? How might certain environmental pollutants exacerbate the health conditions of those who already have a learning, developmental or behavioral disorder?

Twelve leaders and self-advocates* from the learning and developmental disabilities community recently stepped forward to have their bodies tested for the presence of a set of chemicals that are known or suspected to be neurotoxicants, hazardous to nerve cells, or endocrine disruptors with the potential to alter normal hormone function. This report is a synthesis of the results of these tests and the experiences of the participants. It is intended to spotlight these pressing questions and prompt actions to reduce exposures that may impair how we think—and, in the most basic ways, who we are.

A growing number of researchers and health professionals are concerned that some chemicals, found in everyday products, may be disrupting healthy neurological development in unintended ways and potentially intensifying the health concerns of those who already have learning and developmental disabilities.

The Mind, Disrupted Biomonitoring Project tested for the presence of a set of synthetic chemicals and heavy metals, including bisphenol A (BPA), organochlorine pesticides, perchlorate, triclosan, perfluorinated compounds (PFCs), polybrominated diphenyl ethers (PBDEs), lead and mercury. Sixty-one distinct chemicals were detected in the participants. All participants were found to have detectable levels of BPA, mercury, lead, polybrominated diphenyl ethers (PBDEs), perfluorinated compounds (PFCs), perchlorate, and organochlorine pesticides.

This is the first biomonitoring project targeting a particular sector; namely, the learning and developmental disabilities sector. It is important to point out, however, that Mind, Disrupted did not attempt to correlate the presence or levels of chemicals with presence, type or severity of disability. Given the current state of knowledge, no one is able to say that an exposure to a specific chemical causes a specific developmental disability.

Even so, a growing number of researchers and health professionals are concerned that some chemicals, found in everyday products, may be disrupting healthy neurological development in unintended ways and potentially intensifying the health concerns of those who already have learning and developmental disabilities.

“The overwhelming evidence shows that certain environmental exposures can contribute to lifelong learning and developmental disorders,” said Ted Schettler, MD, MPH, Science Director for the Science and Environmental Health Network (SEHN). “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.”

* NOTE: Self-advocates are those individuals with an intellectual, learning, or developmental disability who stand up for their own rights.
The United States Centers for Disease Control and Prevention (CDC) NHANES biomonitoring study indicates that most Americans carry a burden of environmental chemicals in their bodies. These chemical body burdens are unnecessary, preventable, and may be potentially harmful. An updated federal law could result in lowered toxic chemical body burdens, as was demonstrated by biomonitoring studies after lead was better regulated in the United States and PBDEs were banned in Sweden.

In summary, the financial and emotional costs of learning and developmental disabilities are already overwhelming families and communities. In the current health care crisis, we need to take every action possible to prevent and abate the growing incidence of health problems. When we have had the political will to reduce exposure to harmful substances from our environment—such as lead—we have saved billions of dollars as well as increased the quality of life of millions of individuals, families and their communities. We now have the opportunity to fundamentally change the federal law regulating how we develop and produce chemicals, so that the health of current and future generations is not compromised. Reducing exposures to toxic chemicals will in turn lead to a healthier population, and a reduction in health care costs.

This report captures the participants’ experience of being tested and their reflections on what this means for them personally and for society as a whole. The participants in this study—and countless others suffering from chronic disease and disability in which toxic chemicals may play a role—make it very clear that we cannot afford to wait any longer.

As Dr. Ted Schettler said in a recent article in the New York Times in reference to BPA, “When you have 92 percent of the American population exposed to a chemical, this is not one where you want to be wrong. Are we going to quibble over individual rodent studies, or are we going to act?”

In short, the mounting scientific evidence indicates that if we do not reduce our exposure to toxic chemicals and develop safer alternatives, the already-staggering cost of learning and developmental disabilities will likely increase even more, adding millions to those already facing disabilities and unduly undermining their ability to reach their fullest potential.

What a Federal Chemicals Policy Framework Could Provide

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
- 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
Participant Names and Titles

Laura Abulafia, MHS
Location: Los Angeles, California
Title: National Coordinator, Learning and Developmental Disabilities Initiative (LDDI), and Director of Education and Outreach, Environmental Health Initiative, American Association on Intellectual and Developmental Disabilities (AAIDD)

Stephen Boese, MSW
Location: Latham, New York
Title: Executive Director, Learning Disabilities Association of New York State

Robert Fletcher, DSW
Location: Kingston, New York
Title: Founder and CEO, The National Association for the Dually Diagnosed (NADD)

Vernell Jessie
Location: Houston, Texas
Title: Longtime disability advocate and public relations practitioner

David Irons
Location: Atlanta, Georgia
Title: Professional Athlete and Free Agent; cornerback for the NFL’s Atlanta Falcons in 2007–2008; sponsor of summer sports programs for children through his foundation Irons to Impact, or “I2I”

Joseph P. Meadours
Location: Sacramento, California
Title: Executive Director, People First of California

Jeff Sell, Esq.
Location: Bethesda, Maryland
Title: Vice President of Public Policy, The Autism Society (ASA)

Larry B. Silver, MD
Location: Rockville, Maryland
Title: Clinical Professor of Psychiatry, Georgetown University Medical Center; former Acting Director of the National Institute of Mental Health (NIMH); and Past President of the Learning Disabilities Association of America (LDA)

Maureen Swanson, MPA
Location: Pittsburgh, Pennsylvania
Title: Coordinator, Healthy Children Project, Learning Disabilities Association of America (LDA)

Beth Terrill
Location: Chicago, Illinois
Title: Self-Advocate

Cathy Ficker Terrill, MDP
Location: Chicago, Illinois
Title: President and CEO, Ray Graham Association for People with Disabilities; and Past President of the American Association on Mental Retardation (AAMR)-now known as the American Association on Intellectual and Developmental Disabilities (AAIDD)

Ann WingQuest
Location: Anchorage, Alaska
Title: Individual Service Provider, ARC of Anchorage
Mind, Disrupted

An urgent problem

Autism, attention deficit hyperactivity disorder (ADHD), dyslexia, intellectual disability (formerly termed mental retardation), lowered IQ and other disorders of learning, development, and behavior are highly prevalent among American children. Between 1997 and 2006, rates of ADHD diagnosis increased an average of 3% per year. Today, approximately 4.5 million children have been diagnosed with ADHD.

The lifetime prevalence of learning disabilities in United States (U.S.) children is approximately 9.7%, according to a 2007 *Pediatrics* article.

According to a 1994 study, approximately 16% of U.S. children have a developmental disability, and research shows increasing trends.

Since the early 1990s alone, reported cases of autism spectrum disorders have increased tenfold. The United States Centers for Disease Control and Prevention (CDC) now estimates that 1 in 110 US eight-year-olds have autism spectrum disorder, with an increase of 57% between 2002 and 2006.

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

What role do chemicals play?

“Science suggests that exposure to toxic chemicals may contribute substantially to the incidence of learning and developmental disabilities in this society,” said Larry Silver, MD, Clinical Professor of Psychiatry at Georgetown University Medical Center; former Acting Director of the National Institute of Mental Health (NIMH); past president of the Learning Disabilities Association of America; and *Mind, Disrupted* project participant, who has Attention Deficit and Hyperactivity Disorder (ADHD). “This concerns me deeply.”

The effects of chemicals on the nervous system have been recognized since ancient times. Most early reports were the results of high exposures in workers that led to debilitating conditions or even death. For example, over 2000 years ago, the Greek physician Dioscorides wrote that lead exposure “makes the mind give way.”

As science progressed, it was recognized that even small doses of some chemicals result in subtle nervous system impacts that affect an individual’s performance. Chemicals...

Protecting Children After Their Diagnosis

“When Tess was born with Down Syndrome, my husband and I made sure to access all the early intervention services that could help Tess reach her full potential,” said Judith Robinson, a mother of two, Associate Director for the Environmental Health Fund, and a national leader in the movement for environmental health and justice. “But in the next year we learned Tess had been poisoned by the lead paint in our rental apartment.” She continued, “We moved out of our apartment within 24 hours of learning about Tess’s lead levels. But the tougher job of ensuring the products we bring into our new home are free from chemicals associated with the same learning problems that lead can cause is on-going.”
with the capacity to sabotage the development of our brains and nervous systems are termed “developmental neurotoxicants,” while chemicals that interfere with the functioning of our brains are termed “neurotoxic chemicals.”

Many factors influence how vulnerable a person is to the health effects of chemical exposures, among them socioeconomic status, gender, gene expression, nutrition, stress, exposure to infectious agents and timing of exposure. Still, a growing body of peer-reviewed scientific research shows that, for those who are most vulnerable, exposure to even minute doses of neurotoxic chemicals can tip the balance toward learning and developmental disabilities.

According to an article published in the *Lancet* in 2006, “A few industrial chemicals (e.g., lead, methylmercury, polychlorinated biphenyls [PCBs], arsenic, and toluene) are recognised causes of neurodevelopmental disorders and subclinical brain dysfunction” and “another 200 chemicals are known to cause clinical neurotoxic effects in adults.”12 Another review article, linking violent behaviors to chemical exposures, stated that, “A number of environmental exposures are documented to result in a common pattern of neurobehavioral effects, including lowered IQ, shortened attention span, and increased frequency of antisocial behavior.”13 In a study conducted by researchers at the Columbia Center for Children’s Environmental Health, children with higher concentrations of PBDEs (flame retardants) in their umbilical cord blood at birth scored lower on tests of mental and physical development at 1 to 4 and 6 years of age.14 In addition, exposure to mercury from a variety of sources, such as prenatal maternal consumption of seafood high in methylmercury, has been shown to reduce IQ in children.12,15

One intriguing research study that was published in 2009 in the journal NeuroToxicology noted an association between Polyvinyl chloride (PVC) flooring and incidence of autism. While this has not been substantiated, it raises the question about how a range of chemicals—ones we may not even have considered to date—may impact neurological health and how little we truly know about chemical exposure and safety when it comes to human health.16 Another study evaluating “the hypothesis that maternal residence near agricultural pesticide applications during key periods of gestation could be associated with the development of autism spectrum disorders in children,” found that “ASD risk increased with the poundage of organochlorine [pesticides] applied and decreased with distance from field sites.”17 A study of household pesticide use found that “compared with mothers of typically developing children, mothers of children with autism spectrum disorders were twice as likely to report that they had shampooed their pets with pyrethrin-containing antiflea/antitick shampoos around the time of their pregnancy.”18 Yet for the majority of chemicals in use there is a lack of data on potential neurodevelopmental effects from exposure.

A growing body of peer-reviewed scientific research shows that, for those who are most vulnerable, exposure to even minute doses of neurotoxic chemicals can tip the balance toward learning and developmental disabilities.

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.19 And yet, chemicals known and suspected to be neurotoxic are present in our air, water, food consumer products, homes and workplaces—and, as this project demonstrates, in our bodies.

“I have cerebral palsy,” responds Ann WingQuest. “I’m very sensitive to the fact that people with developmental disabilities have compromised systems, and introducing any kinds of toxins to their systems complicates everything. The current policy approach to dealing with our environment makes it clear that [when it comes to managing chemicals] we have no idea what we’re doing. And that really concerns me.”

Our nation’s primary law concerning toxic chemicals, the Toxic Substances Control Act (TSCA), became law in 1976. Since its passage, evidence has been accumulating that chemicals such as lead, mercury, bisphenol A (BPA) and PBDEs may harm the developing brain at levels much lower than those previously considered safe. TSCA has not been updated to reflect our better understanding of toxic chemicals.

Meanwhile, many chemicals in common use remain untested. A U.S. Environmental Protection Agency (EPA) analysis revealed that, of the roughly 3,000 chemicals produced or imported in the U.S. in quantities over 1 million pounds a year, only 43% have been tested for basic toxicity, and a scant 7% have been subjected to the six tests considered “necessary for a minimum understanding of a chemical’s toxicity” (among which is a test for basic developmental and reproductive toxicity).20
“These chemicals are not supposed to end up in our bodies,” says project participant Cathy Ficker Terrill, President and CEO of the Ray Graham Association for People with Disabilities. Cathy’s daughter, Beth Terrill, a self-advocate, has a developmental disability and chemical sensitivities, and is also a participant in *Mind, Disrupted*.

**An unacceptable cost**

While learning and developmental disabilities can offer unique gifts and perspectives, they also impose significant costs, among them medical care, special education and therapies, diminished productivity, and long-term care.

The limited data available on the economic impacts of learning and developmental disabilities are sobering. For instance, the lifetime cost of caring for a child with autism has been estimated at $3.2 million.21 The U.S. spends an estimated $352-602 billion annually on autism-related costs alone.

Other learning and developmental disabilities also bear hefty price tags. The estimated average lifetime cost for one person with intellectual disability is just over a million dollars.24 A review in the *Journal of Pediatric Psychology* estimated the annual societal cost of ADHD in children and adolescents to be between $36 and $52 billion (in 2005 dollars), a figure that includes costs for treatment, special education, and parental work loss.25

Yet such statistics are inadequate to capture the emotional and social toll of learning and developmental disabilities on those affected, their families, and their caregivers. David Irons, Professional Athlete and *Mind, Disrupted* project participant says, “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 making it harder to achieve our goals.”

Stephen Boese, MSW, Executive Director of the Learning Disabilities Association of New York State adds, “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.”

If the incidence of learning and developmental disabilities continues to climb, so will the enormous financial and social cost. Are we prepared to invest in sufficient schools, care facilities, and occupational programs to accommodate a society in which 1 in 110 individuals are diagnosed with autism and other learning and developmental disabilities are also common?26

When the U.S. had the political will to remove most lead from the environment, society saved billions of dollars in healthcare costs and gained billions in boosted productivity. We are still seeing the benefits of that choice.2

The CDC reports that as of 2005, nearly half of all Americans live with at least one chronic disease, and these diseases are responsible for 75% of U.S. health care costs.27 A January 2010 report by the Safer Chemicals, Healthy Families Campaign, “The Health Case for Reforming the Toxic Substances Control Act,” points out: “Even if chemical policy reform leads to reductions in toxic chemical exposures that translate into just a tenth of one percent reduction of health care costs, it would save the U.S. health care system an estimated $5 billion every year.”

Phil Landrigan, MD, MSc, of the Children’s Environmental Health Center at the Mount Sinai School of Medicine, said, “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.”29
Mind, Disrupted: Findings

In 2009, twelve leaders and self-advocates from the learning and developmental disabilities community volunteered to have their bodies tested for 89 chemicals known or suspected of being neurodevelopmental toxicants or endocrine disruptors, including bisphenol A, lead, mercury, organochlorine pesticides, polybrominated diphenyl ethers (PBDEs), perchlorate, perfluorinated compounds (PFCs), and triclosan.

Participant body burdens
A total of 61 chemicals (out of 89 tested) were found in the twelve participants. Each participant was found to harbor at least 26, and as many as 38, of the tested chemicals in their bodies. Sixteen chemicals were detected in every participant.

Bisphenol A
A chemical used to make epoxy resin to line food cans and other containers; the building block for polycarbonate plastic; present in paper products

<table>
<thead>
<tr>
<th>Participant</th>
<th>Bisphenol A (µg BP A/g creatine) ppm</th>
</tr>
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<tbody>
<tr>
<td>Cathy Terrace</td>
<td>10.5</td>
</tr>
<tr>
<td>Vernell Jessie Terrill</td>
<td>12.0</td>
</tr>
<tr>
<td>Beth Terrill</td>
<td>8.0</td>
</tr>
<tr>
<td>Larry Silver</td>
<td>6.0</td>
</tr>
<tr>
<td>Laura Abdulia</td>
<td>4.0</td>
</tr>
<tr>
<td>Maureen Swanson</td>
<td>2.0</td>
</tr>
<tr>
<td>Amy WingQuest</td>
<td>2.0</td>
</tr>
<tr>
<td>Joe Maddox</td>
<td>1.0</td>
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<tr>
<td>Stephen Bose</td>
<td>1.0</td>
</tr>
<tr>
<td>Jeff Salt</td>
<td>0.5</td>
</tr>
<tr>
<td>Robert Fletcher</td>
<td>0.5</td>
</tr>
</tbody>
</table>

Bisphenol A concentrations in Participant Urine (creatinine adjusted)

CDC 95th percentile for BPA in urine

CDC average for BPA in urine

NOTE: A table indicating the body burden levels of all the participants can be found in the Appendix. The Mind, Disrupted project tested twelve participants’ blood, however one participant (David Irons) chose not to have his urine tested, which explains why some charts show all twelve participants and those charts that indicate chemicals tested from urine samples only show eleven participants.
“I was interested to see what chemicals were in my body. When I was a child, I used to play with mercury quite often. My father was a dentist and worked out of the house. Also, years ago, I wasn’t aware of any health effects of lead, so I used to bite on the lead weight when I went fishing. I have a significant learning disability—dyslexia—and since I’ve become more aware of neurotoxic agents, it raises the question in me whether these exposures contributed to my disability.”

Robert Fletcher, DSW
Founder and CEO of the National Association for the Dually Diagnosed

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Laura Abulafia, MHS
National Coordinator for LDDI and Director of Education and Outreach for AAIDD’s Environmental Health Initiative.

NOTE: A table indicating the body burden levels of all the participants can be found in the Appendix.
Four organochlorine pesticides or pesticide metabolites

- **Hexachlorobenzene** – a byproduct during the manufacture of pesticides and solvents
- **Beta-hexachlorocyclohexane (Beta-HCH)** – a byproduct formed during the production of lindane (gamma HCH). Lindane is a pesticide banned for agricultural use in the U.S., but still approved by the Food and Drug Administration (FDA) for treating head-lice and scabies.
- **Trans-nonachlor** – a constituent of the insecticide chlordane, now banned in the U.S.
- **p,p-DDE** – metabolite of the pesticide DDT, the use of which was banned in the U.S. in 1972

“It is disturbing that even though it’s been a long time since DDT has been banned as a pesticide in the U.S., it still exists and builds up in our bodies. It’s disturbing that it has that kind of staying power long term. I do have an 18 year old and I figure that whatever might be going on in my body might certainly be going on in her body. It’s very disturbing to think that a chemical that was banned decades ago may still be taking up residence in the body of my child.”

Vernell Jessie
Longtime disability advocate and public relations participant
“It’s important that as companies phase out toxic chemicals such as some of the PBDEs, they thoroughly test the substituted chemicals for development toxicity and that the results of their analyses are made available to manufacturers who will be using these substitutions in their products.”

Stephen Boese, MSw  
Executive Director, Learning Disabilities Association of New York State

“Low thyroid functioning in the mother may impact the fetus, and if we can prevent exposures to toxic chemicals, such as perchlorate, then we would potentially have an enormous impact on the rates of learning and developmental delays.”

Larry Silver, MD  
Clinical Professor of Psychiatry, Georgetown University Medical Center; former Acting Director of the National Institute of Mental Health (NIMH)

**Six PBDEs**  
Polybrominated diphenyl ethers, a class of flame retardant chemicals used in construction, electronics and furniture upholstery

**Perchlorate**  
A chemical used in rocket fuel, road flares, airbags

**NOTE:** A table indicating the body burden levels of all the participants can be found in the Appendix.
Perfluorinated compounds PFOS and PFOA
Perfluorinated compounds used to make consumer and household products water, stain and grease repellant

“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
Self-advocate and Executive Director of People First of California

Triclosan
Used in antibacterial soaps, toothpaste, and other personal care products

“I started going green before people really started going green and 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

NOTE: A table indicating the body burden levels of all the participants can be found in the Appendix.
Learning and developmental disabilities and toxic chemical exposures

The role of environmental factors—particularly toxic chemical exposures—in the onset, trajectory, and overall incidence of a number of diseases and disabilities is often overlooked. While adverse health outcomes are the result of a complex interplay of multiple factors, including heredity, gene-environment interaction, nutrition, and socioeconomic status, both laboratory and human studies indicate that toxic chemical exposures may play a role. Scientific evidence implicates environmental exposures as discernable contributors to adverse health outcomes, such as cancer, neurodegenerative diseases, reproductive health problems, and learning and developmental disabilities. It is important to note that both the dosage and the timing of exposure have significant roles in determining potential health outcome. The presence of environmental chemicals in the human body does not necessarily imply that they are causing adverse health effects.

The following is a list of the chemicals included in this study and some of the health outcomes that have been associated with exposure to them. This list serves as a quick reference and a shorthand introduction to the chemical fact sheets found on the Mind, Disrupted website at www.minddisrupted.org. For many of these chemicals, it is not possible to prove that they are responsible for adverse health outcomes in humans. Information regarding the neurotoxicity or developmental neurotoxicity of these chemicals is often from laboratory experiments, typically with animal subjects. Conclusive human epidemiological studies are rare. The scientific community must rely on the weight of evidence that these chemicals can alter development or disrupt normal brain function. For some chemicals, the weight of evidence is strong enough for the scientific community to accept a causal relationship; for others this strong connection has yet to be established, and may never be. Regardless, precaution dictates that we take action to reduce and eliminate harmful exposures.

Information about these chemicals was gathered from primary research and review articles. The actions of these chemicals, suspected of disrupting normal neurological development or functioning, are included with citations. In cases where there is a lack of human data, animal studies are used to provide evidence of adverse effects. While toxicity research conducted on animals is not conclusive, animal toxicological studies have been shown to help predict human health impacts.

These chemicals are known or suspected to adversely affect human health, and specifically neurodevelopment. The weight of evidence for adverse outcomes varies with each chemical, and is represented below.

**Bisphenol A**

**Animal:** BPA has estrogenic activity and as such alters both sexual development and neurobehavior. BPA blocked the receptors for estradiol in the hippocampus and prefrontal cortex of rodents and non-human primates. BPA was found to reduce nerve cell density in certain parts of the mouse brain. A study of mice found that prenatal exposure to BPA produced memory impairments.

**Human:** Prenatal BPA exposure is associated with altered behavior in two-year old children, especially females.

**Lead**

**Human:** Prenatal exposure to lead is associated with premature births, reduced growth, learning difficulties and decreased IQ. Exposures to lead are also associated with neuropsychiatric disorders such as attention deficit hyperactivity disorder (ADHD) and antisocial behavior. There is also evidence that lead damages brain tissue.

Research shows that there is no safe level of exposure to lead in children. Early exposure to lead has been reported to lead to juvenile delinquency.
Mercury

**Human:** Reported neurobehavioral effects of mercury exposure include altered motor function and memory, as well as learning disabilities.\(^{45}\) Developing fetuses and children are particularly vulnerable to impairment of the developing central nervous system, as well as pulmonary and nephrotic damage.\(^{46,47,48}\)

**Organochlorine pesticides**

**Animal:** Exposure to organochlorine pesticides has been associated with permanent behavioral changes, and altered androgen levels in rats.\(^{49,50}\)

**Human:** Exposure to organochlorine pesticides has been associated to decreased psychomotor function and mental function, including memory, attention, and verbal skills in children.\(^{51,52,53}\) Much of this research was carried out in children raised in agricultural areas with exposures that are higher than in non-agricultural areas.

PBDEs

**Animal:** Numerous studies on rodents suggest that neonatal exposure to PBDEs permanently affects learning and memory functions, impairs motor activity, and is associated with aberrations in spontaneous motor behavior and hyperactivity.\(^{54,55,56}\)

**Human:** Prenatally exposed children demonstrated impaired fine motor skills and attention.\(^{57}\) Elevated levels of PBDEs 47, 99 and 100 in umbilical cord blood were correlated with lower scores on multiple developmental tests in children.\(^{14}\) These studies evaluated effects at typical exposure levels for the U.S. population.

### Associations Between Health Outcomes and Exposures

#### Attention Deficit and Hyperactivity Disorders (ADHD)

According to the National Institute of Mental Health (NIMH), ADHD is one of the most common childhood disorders and can persist throughout life. Symptoms include hyperactivity and difficulty staying focused, paying attention, and controlling behavior.\(^{58}\)

**Chemical exposures associated with ADHD:**
- Strong evidence: ethanol, lead, PCBs
- Good Evidence: manganese, solvents, tobacco smoke
- Some evidence: multiple pesticides, cadmium, PBDEs

#### Cognitive disability / Intellectual disability /
**Developmental delays**

Persistent, major delay in one or more areas of early childhood development, such as communication, social and motor skills.\(^{59}\)

**Chemical exposures associated with developmental delays:**
- Strong evidence: ethanol, lead, mercury, PCBs, tobacco smoke
- Good evidence: carbon monoxide, multiple pesticides, solvents
- Limited evidence: arsenic, cadmium, fluoride, PBDEs

#### Behavioral disorders

Chronic hostile, aggressive or disruptive behaviors.\(^{60}\)

**Chemical exposures associated with behavioral disorders:**
- Strong evidence: ethanol, lead, mercury, PCBs
- Good evidence: nicotine
- Limited evidence: multiple pesticides

#### Psychomotor delays /decreased coordination

A generalized slowing of physical and /or mental reaction.\(^{61}\)

**Chemical exposures associated with psychomotor delays:**
- Strong evidence: lead, mercury, carbon disulfide, acrylamide
- Good evidence: multiple pesticides, solvents, aluminum, manganese, methyl bromide
- Limited evidence: styrene, toluene

#### Psychiatric disorders

Any of a multitude mental illnesses including disorientation, hallucinations, psychosis, delirium, paranoia, anxiety/depression, emotional lability, mood changes, euphoria.\(^{62}\)

**Chemical exposures associated with psychiatric disorders:**
- Strong evidence: ethanol, lead, mercury, carbon disulfide
- Good evidence: multiple pesticides, manganese, methyl bromide
- Limited evidence: acrylamide, thallium
Perchlorate

**Animal:** Maternal perchlorate exposure was associated with a reduction of iodine in breast milk and a reduction in neonatal thyroid hormone levels in rats.63

**Human:** High doses of perchlorate cause changes in iodine uptake but not thyroid hormones in otherwise healthy individuals.64 Women with low iodine levels were likely to have decreased T₄ when exposed to perchlorate.65

Research suggests that maternal perchlorate exposure during pregnancy could potentially cause abnormal development through hypothyroidism.66

PFCs

**Animal:** Adult mice that were prenatally exposed to PFOA and PFOS displayed decreased spontaneous behavior, increased hyperactivity, and lack of habituation to a new environment.67

**Human:** PFOA and PFOS exposure in utero has also been associated with small reductions in birth weight in newborn babies at typical exposure levels for the U.S. population.68,69

Triclosan

**Animal:** Triclosan disrupts thyroid hormone function in rats70,71 and disrupts normal physical development in frogs.72 Triclosan disrupts normal estrogen transportation pathways in sheep placenta.73

The Collaborative on Health and the Environment (CHE) maintains a Toxicant and Disease Database, compiling information on health effects of toxic substances. This information was used in the following summary of environmental chemicals known or suspected to contribute to adverse health outcomes.

The database codes the strength of the available evidence into three categories. The evidence of a link between exposure to a given chemical and a given health outcome was classified as “strong” if a causal association between exposure and outcome has been conclusively established in humans and is accepted in the medical community. Evidence is classified as “good” when exposure has been associated with a health outcome through epidemiological studies or through “some human evidence and strong corroborating animal evidence.” “Limited” evidence indicates that the chemicals listed have been mildly associated with a health outcome by limited case reports, human epidemiological studies with mixed or equivocal results, or from “reports clearly demonstrating toxicity in animals where no human data exist.”

Vulnerable populations

Some populations are especially vulnerable to the potential health effects of toxic chemical exposures, including:

THE DEVELOPING FETUS

The timing of a toxic chemical exposure can change the presence, type, or severity of the health effects from that exposure. Exposures during gestation (development in the womb), in particular, can have serious health consequences.

Prenatal development, particularly brain development, proceeds at a blistering pace. “Neuroendocrine chemicals are very busy within the first months of pregnancy,” said Larry Silver, MD.

The developing fetus is extraordinarily vulnerable to the potential effects of exposure to neurotoxic chemicals for several reasons. As Drs. Grandjean and Landrigan noted in an article published in the *Lancet*, “during the nine months of fetal life, the human brain must develop from a strip of cells along the dorsal ectoderm of the fetus into a complex organ consisting of billions of precisely located, highly interconnected, and specialized cells” and thus “windows of unique susceptibility to toxic interference arise that have no counterpart in the mature brain, or in any other organ.”12

Also, the placenta (a temporary organ that provides the fetus with oxygen and nutrients) does not shield the fetus from all toxic chemical exposures. The fetus has limited ability to metabolize and excrete toxins compared to adults, and the blood-brain barrier that protects mature brains from many chemical exposures is still forming until about six months after birth.74

Chemical Case Study: Thyroid and brain development

The thyroid gland controls how quickly the body uses energy, makes proteins, and controls how sensitive the body should be to other hormones. Good thyroid functioning is critical for good health. Healthy functioning of the thyroid can be damaged by exposures to chemicals such as PCBs,75,76 dioxin, perchlorate,74 bisphenol A,77 and polybrominated diphenyl ethers (PBDEs).78

Low thyroid hormone levels in the fetus have been associated with developmental delays, visual impairment, memory and cognition problems, and lowered IQ. The fetus must rely on maternal thyroid hormones until its
own thyroid is functioning, usually in the second trimester. If the mother herself is low in the thyroid hormone (T₄), she may be unable to provide the amount of thyroid hormone necessary to the fetus, whose neurological system may consequently be impaired.

Perchlorate is a chemical used in the manufacturing of rocket fuel, road flares and airbags. We are exposed to perchlorate through drinking water, produce and dairy products. Perchlorate can inhibit the production of T₄ by preventing the thyroid from taking up a building block for T₃, iodine, from the blood stream. Iodine is used in the body’s production of T₃. We obtain iodine from eating iodine-containing foods such as fish, dairy products and plants grown in soil rich in iodine.

The CDC has found that 36% of women in the United States have less than optimal levels of iodine in their bodies. The CDC also reports that we all carry detectable levels of perchlorate in our bodies, which means that those women with already low iodine levels may be more likely to have a dysfunctional thyroid, i.e. a thyroid not producing adequate amounts of thyroid hormone (TH). Despite this, there are no federal standards regulating the amount of perchlorate in our drinking water.

Larry Silver, MD states, “We know that alcohol use and smoking might impact the fetus so we tell the parents please don’t smoke, don’t drink, and don’t use drugs… We know that the thyroid can be harmed by a variety of toxic chemicals but we don’t protect women of child bearing age from these chemicals. Low thyroid functioning in the mother may impact the fetus, and if we can prevent exposures to these toxic chemicals, then we would potentially have an enormous impact on the rates of learning and developmental delays.”

Chemical Case Study: Prenatal BPA exposure associated with aggression, hyperactivity in two-year-old girls
Researchers from the University of North Carolina and Simon Fraser University in British Columbia measured BPA concentrations in the urine of about 250 pregnant women in Cincinnati, Ohio at 16 and 26 weeks of gestation, and again at birth. Two years later, the behavior of the women’s children was assessed using the Behavioral Assessment System for Children.

After adjusting the data for confounding factors, the researchers found that BPA concentrations at 16 weeks of gestation were more strongly associated with externalizing scores than concentrations at 26 weeks or birth. “Externalizing” behavior includes hyperactivity and aggression. The association between higher BPA concentrations at 16 weeks and above-average externalizing scores was much stronger in female offspring.

Researcher Bruce Lanphear, MD, MPH, Faculty of Health Sciences at Simon Fraser University, was quoted as saying, “The girls showed a definite difference in temperaments. Their behavior was actually much more like [the behavior of] boys at the same age.”

CHILDREN
Cathy Ficker Terrill states: “Having a child with complex allergies made [my family] very interested in learning about toxic chemicals. Since our daughter has environmental allergies our family has always been interested in living in a clean and safe environment. We were shocked by our chemical body burden results because we have been living in an allergy free house since Beth was 8.”

Brain and nervous system development continues through early childhood and into adolescence; the period of vulnerability to toxic chemical exposures stretches accordingly.
At the same time, infancy and childhood bring new sources of exposure to toxic chemicals. As the Learning and Developmental Disabilities Initiative (LDDI) Scientific Consensus Statement on Environmental Agents Associated with Neurodevelopmental Disorders (hereafter referred to as “LDDI Scientific Consensus Statement”) notes: relative to their body weight, “children eat and breathe more than adults, thus a small exposure translates into a big dose.” The LDDI Scientific Consensus Statement also states that there is growing evidence that stress, when combined with social ecology or environmental exposures can increase a child’s susceptibility to developmental disorders.29

Joe Meadors has voiced concerns about his parents’ likely exposures during his conception and gestation to a wide range of pesticides used in the southeast U.S. His father was a crop duster, and Joe remembers waving to his father’s plane as it flew overhead, spraying pesticides on the fields where he and his brother were playing. Joe states, “I can’t help but wonder if that caused or contributed to my developmental disability.”

PEOPLE WITH LEARNING AND DEVELOPMENTAL DISABILITIES
Exposure to neurotoxic chemicals may exacerbate existing learning and developmental disabilities. For example, every 1 µg/dL (microgram per deciliter) increase in average lifetime blood lead level (while still under the CDC’s 10 µg/dL level of concern of concern) results in an average IQ decrease of 1.37 points.82 That may sound like a negligible effect. But a one-point IQ increase has been estimated to translate into a 1.8–2.4% increase in lifetime earnings.83 For someone with intellectual disability, a handful of IQ points can mean the difference between being able to hold a job and live independently or not.

Beth Terrill explains, “Knowing that these chemicals are in us helps inform other people about toxic chemicals so they can then choose more carefully what to do and what to eat. I get headaches when I’m around paint or other chemicals in the house. I also get stomach aches. I also worry about being around chemicals that are used to kill bugs.”

Infants and young children with developmental disabilities may spend more time in the crawling stage of development than those without such disabilities, thus spending a greater portion of their early childhood exposed to dirt and dust on the floor. More time on the floor could, in turn, translate to higher intake of toxic chemicals that migrate from objects to household dust. A 2009 study estimated that ingestion and dermal absorption of household dust accounts for 56–77% of total intake of PBDEs (flame retardants) in toddlers, children, and adults. The same study calculated the daily estimated exposure to PBDEs of toddlers to be 13.3 nanograms per kilogram of body weight per day—over four times greater than the daily estimated exposure of adults.84

Also, children and adults with developmental disabilities may be more prone to pica behaviors (ingesting non-food items at developmentally inappropriate ages), which can lead to lead poisoning85 and likely increase other toxic chemical exposures.

Because of difficulty in reading or interpreting warnings about toxic chemical exposures, some adults with learning and developmental disabilities may be more prone to toxic exposures. For example, they may find it difficult to decipher labels listing toxic ingredients or understand cautionary notices about fish consumption and mercury.

“How can I choose safe products when companies don’t tell me what ingredients are in the products I like to use,” asks Joe Meadors. “I want to protect my health but companies make this difficult. Old ways are hard to break, but really, why can’t products I use be free from harmful chemicals?”

“No one gets a pass on these exposures,” said Judy Robinson. “Yet the consequences of chemical exposure for one person...”
Many of the chemicals tested for in the *Mind, Disrupted* project are considered to be endocrine-disrupting chemicals (EDCs), such as BPA, PBDEs, and DDT (an organochlorine pesticide). The human endocrine (hormone) system is a key part of the development and functioning of the body, starting with gestation and continuing throughout a person’s life.88

In 2009, the Endocrine Society, an international body of 14,000 members dedicated to research on hormones and the clinical practice of endocrinology, released a key scientific statement concerning the health threats of endocrine-disrupting chemicals. The statement says, in part: “EDCs can have neurobiological and neurotoxic effects… Numerous neurotransmitter systems such as dopamine, nor epinephrine, serotonin, glutamate, and others are sensitive to endocrine disruption. This point is important because it explains neurological effects of EDCs on cognition, learning, memory, and other non-reproductive behaviors.”89 A growing number of synthetic (manmade) chemicals, including chemicals in widespread use such as BPA, phthalates, and many pesticides, have been found to interfere with the endocrine system.90

Exposure to even very small doses of “endocrine disruptors” can wreak subtle or serious havoc with the human endocrine system, which is remarkably sensitive. According to The Endocrine Disruptor Exchange, a non-profit website founded by Dr. Theo Colborn that compiles research on endocrine disruptors, “The endocrine system is so fine tuned that it depends upon changes in hormones in concentrations as little as a tenth of a trillion of a gram to control the womb environment. That’s as inconspicuous as one second in 3,169 centuries.”91 The health effects of disruption of the endocrine system may not manifest until later in life. Those effects can include impaired brain development (through interference with thyroid hormone levels), diminished ability to control behavior, an increased risk of reproductive health problems, and other issues.

Jeff Sell, participant and father of two boys with autism states: “I would like to think I’ve got a fairly decent understanding of all these chemicals, but it can make your head spin. I’ve said for years that if you ask 10 different physicians about the causes of autism, you’ll get 10 different answers; as a parent of two boys with autism it’s very frustrating because I can’t help but wonder, stepping back from my own personal history, about what I’ve been exposed to. It’s amazing to me how much body burden I have and what that means for my children.”92

Industrial chemicals are not routinely tested for hormonal or very-low-dose effects. Despite this, the list of industrial chemicals known or suspected to disrupt the endocrine system continues to grow.
Why Are Human Bodies and the Environment Contaminated with Toxic Chemicals?

The Toxic Substances Control Act (TSCA) of 1976 is the primary federal policy intended to protect the public from hazardous chemical exposures. But TSCA is outdated and ineffective. Contrary to popular belief, chemicals do not have to undergo basic testing of their health and safety prior to going on the market.

“I feel like I’m in a vacuum,” states Ann WingQuest, participant with cerebral palsy who lives in Alaska, “because I don’t know the manufacturers and I have no way of telling them that they need to be more careful about the chemicals they put in their products.”

We know little about the neurodevelopmental and other health effects of the 82,000 chemicals registered for U.S. commerce today. Roughly 7% of chemicals in use have been subjected to testing thorough enough to determine developmental or reproductive toxicity. Given the enormous number of untested industrial chemicals in use, the total number of neurotoxic chemicals in commerce is likely to be substantial.

“My body is my life, states Cathy Flicker Terrill, and just as the government regulates the banking industry, they have an obligation to regulate the poisons and toxins in our environment. For many years they knowingly dumped poisons in our rivers and lakes and other waterways. I also believe that these toxins are causing some of these high rates of disabilities. We don’t even know what the effects are on our bodies or the long term effects to the public are.”

At present TSCA does not adequately regulate and control chemical to prevent harm. Standard toxicity testing does not predict the effects of very-low-dose, cumulative, or synergistic chemical exposures. We need to update federal law in a way that reflects the science of the past 34 years.

For example, scientists discovered that a major tenet of toxicology—that the biological impact of exposure to a chemical is proportional to the size of the dose (or “the dose makes the poison”)—is not always true. Put another way, exposure to very small doses of some...
chemicals appears to have a greater impact than slightly larger doses. This effect seems most consistent with hormonally active chemicals, such as BPA, hexachlorobenzene (an organochlorine pesticide), and DEHP (a chemical in a class of multifunctional chemicals called phthalates, which are used in a wide array of consumer products and industrial processes).94

Scientists have also moved forward in considering all the factors that impact the body’s capacity to withstand exposures to toxic chemicals. For example, a report by the National Research Council (NRC) of the National Academy of Sciences (NAS), “Phthalates and Cumulative Risk Assessment,” is calling for a better assessment of cumulative risk factors, which can modify the effects of any toxic chemical. Cumulative risk, in a broad sense, means, “the risk posed by multiple chemicals and other stressors that cause varied health effects and to which people are exposed by multiple pathways and exposure routes and for varied durations”—in other words, stress, nutrition, gene-environment interaction, exposure to infectious agents, and other factors can modify the effects of toxic chemical exposures on an individual or a community.95

The NRC report also calls for considering exposures to all chemicals associated with common adverse health outcome, rather than simply considering chemicals that operate by similar mechanisms in developing risk assessments. For example, the report suggests, “EPA could evaluate combined exposures to lead, methylmercury and polychlorinated biphenyls because all contribute to cumulative risk of cognitive deficits consistent with IQ reduction in children, although the deficits are produced by different mechanisms of action.”95 Doing so, the report concludes, would reinforce EPA’s capacity to fulfill its mandate of protecting human health.

A 2007 report commissioned by the EPA and written by the NRC proposed a paradigm shift that would greatly improve “how scientists evaluate the health risks posed by potentially toxic chemicals found at low levels in the environment. These advances would make toxicity testing quicker, less expensive, and more directly relevant to human exposures.”96

The report overview conceded that such a shift would “require a substantial commitment of resources, the involvement of multiple organizations in government, academia, industry, and the public, and… take time (10-20 years) to achieve.”96

In order to develop and implement effective toxicity testing, we need the federal government to demonstrate a strong, sustained commitment to chemical policy reform.
POLICY RECOMMENDATIONS: What We Can Do to Prevent Unnecessary Exposure to Toxic Chemicals

Prevention of learning and developmental disabilities is both an individual and a community responsibility,” says Stephen Boese, MSW. However, current laws “simply do not work, and have done virtually nothing to assure Americans that our everyday products are safe for use.”

As individuals, we make choices in consumption and lifestyle that may reduce our own exposure to toxic chemicals. But individuals cannot avoid toxic chemicals entirely and should not have to bear the burden of finding safe products. Instead, we need to ensure chemicals are safe and tested prior to entering our consumer goods, homes and bodies.

Laura Abulafia, MHS, a young woman engaged to be married, finds it disquieting to consider the effects of toxic chemical exposures on the family she and her future husband hope to have.

“With all that we know about these chemicals—like mercury, lead, and BPA—and with all the research out there on advanced technologies that would allow us to move away from using these chemicals in our industries and in our daily products, I’m deeply disturbed and feel very helpless that these known toxic chemicals are still being used, still left unregulated.

“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.”

Patching the chemical safety net: Ten policy steps to protect our health, potential, and future

A reformed Toxic Substances Control Act (TSCA) would serve as the backbone of a sound and comprehensive chemicals policy that protects public health and the environment, while restoring the luster of safety to U.S. goods in the world market. Any effective reform of TSCA should:

1. **Immediately Initiate Action on the Worst Chemicals**
   Persistent, bioaccumulative toxicants (PBTs) are uniquely hazardous. Any such chemical to which people could be exposed should be phased out of commerce. Exposure to other toxic chemicals, such as formaldehyde, that have already been extensively studied, should be reduced to the maximum extent feasible.
2. **Require Basic Information for All Chemicals**
Manufacturers should be required to provide basic information on the health hazards associated with their chemicals, how they are used, and the ways that the public or workers could be exposed.

3. **Protect the Most Vulnerable**
Chemicals should be assessed against a health standard that explicitly requires protection of the most vulnerable subpopulations. That population is likely to be children, but it could also be workers, pregnant women, or another vulnerable population.

4. **Use the Best Science and Methods**
The National Academy of Sciences’ recommendations for reforming risk assessment at the Environmental Protection Agency (EPA) should be adopted. Regulators should expand development and use of information gleaned from “biomonitoring,” the science of detecting human chemical contamination, to inform and impel efforts to reduce these exposures.

5. **Hold Industry Responsible for Demonstrating Chemical Safety**
Unlike pharmaceuticals, chemicals are currently presumed safe until proven harmful. The burden of proving harm falls entirely on EPA. Instead, chemical manufacturers should be responsible for demonstrating the safety of their products.

6. **Ensure Environmental Justice**
Effective reform should contribute substantially to reducing the disproportionate burden of toxic chemical exposure placed on people of color, low-income people and indigenous communities.

7. **Enhance Government Coordination**
The EPA should work effectively with other agencies, such as FDA, that have jurisdiction over some chemical exposures. The ability of the states to enact tougher chemical policies should be maintained and state/federal cooperation on chemical safety encouraged.

8. **Promote Safer Alternatives**
There should be national support for basic and applied research into green chemistry and engineering, and policy should favor chemicals and products that are shown to be benign over those with potential health hazards.

9. **Ensure the Right to Know**
The public, workers, and the marketplace should have full access to information about the health and environmental hazards of chemicals and the way in which government safety decisions are made.

10. **Require Labeling of Chemical Ingredients in Products**
Many of the everyday products we use that may have been formulated with toxic chemicals are not required to label the use of these ingredients, both active and inert. Some fabrics, for example, are treated with PFCs to prevent staining or with some forms of PBDEs in order to make them fire-resistant. Full disclosure of product ingredients will allow consumers, retailers and businesses to make informed decisions.

PBDEs and breast milk: A Swedish biomonitoring success story

In 1998, as described in a 2003 commentary in the peer-reviewed journal *Environmental Health Perspectives*, analysis of archived breast milk samples in Sweden showed that PBDE levels in breast milk had been doubling every five years for the previous 25 years. Use of PBDEs was subsequently phased out in Sweden. Measurements have shown a steep decline in levels of PBDEs in breast milk following the phase-out. In the same time period, levels of PBDEs in North American breast milk have skyrocketed, exposing our tiniest and most vulnerable citizens to a known neurotoxin in the very first hours of their lives.
Appendix: Methods and Total Results

Reference data
Concentrations of chemicals found in participants of this project were compared to data from the National Health and Nutrition Examination Survey (NHANES) conducted by the CDC. The NHANES is an ongoing project of the CDC that aims to gather baseline information about the health of the U.S. population. The most recent published data from NHANES at the time of the *Mind, Disrupted* project (2009) was employed at all times.

When possible, reference data from the NHANES 2003-2004 data collection period were used. The reference data for PFCs (perfluorinated compounds) and perchlorate is from NHANES 2001-2002. The reference data for mercury included data collected as recently as 2006, while the reference data for lead was collected no later than 2000.

“CDC average” is the average (geometric mean) concentration in the total NHANES study population. “CDC 95th percentile” is the average (geometric mean) concentration of the chemical in the 5% of the NHANES population with the highest concentrations.

Data not found in graphs
Concentrations that were below the limit of detection (LOD) are graphically reported as zero. Chemicals below the limit of detection are not necessary absent from the sample; they could be present at levels below those that the present technology can detect.

Some chemicals were detected, but at concentrations too low to accurately quantify. Concentrations detected below the limit of quantification (LOQ) were graphically reported as zero in graphs including all of the study participants. Some of the chemicals analyzed were below the LOD or LOQ in all participants. Data for those chemicals were not included in the graphs. Any data not included in the graphs may be found in the data tables.

Testing chemicals in urine
The analysis of chemical data from urine testing is more complicated than the analysis of chemical data from blood testing. The concentrations of both natural substances and toxins in urine change based on how hydrated a person is, what time of day it is, or what he or she ate recently. To account for this difference, a naturally occurring chemical called creatinine, which is present in all urine, is measured along with the other chemicals being studied. Knowing the concentration of creatinine in the urine makes it easier to compare the results of different people.

The process of using creatinine to standardize urine results is called “creatinine adjustment.” When creatinine adjustment has been used, it is indicated on the graph.

Results
Sixty-one toxic substances were detected at quantifiable concentrations in the twelve participants. Each participant had quantifiable concentrations of 26-38 toxic substances. Sixteen toxic substances were detected in every participant: bisphenol A, mercury, lead, Hexachlorobenzene, Beta-HCH, trans-nonachlor, p,p-DDE, PFOS, PFOA, perchlorate, and PBDE 15, 28/33, 47, 99, 100, and 153.
Bisphenol A (BPA)

BPA was detected in all the participants. It was above the CDC average in four participants, and above the 95th percentile in one of those four participants.

Heavy metals

Both mercury and lead were detected at quantifiable concentrations in all participants. Mercury concentrations were above the CDC average in ten participants and above the 95th percentile in two of those participants. Lead concentrations were above the CDC average in three participants.

Organochlorine pesticides

Seventeen organochlorine pesticides were detected in the participants. Between seven and eleven organochlorine pesticides were detected in each participant. Four organochlorine pesticides were detected in all participants: hexachlorobenzene, Beta-HCH, trans-nonachlor, and p,p-DDE. The major metabolite of DDT, p,p-DDE, was detected at the highest concentration of any organochlorine pesticide.

- One participant was above the CDC average for hexachlorobenzene.
- Four participants were above the CDC average for oxychlordane.
- Four participants were above the CDC average for trans-nonachlor.
- One participant was above the CDC average for p,p-DDE.

Polybrominated diphenyl ethers (PBDEs)

All participants had quantifiable concentrations of 10–20 PBDEs in their bodies. A total of 34 PBDE congeners were detected. PBDE congeners 15, 28/33, 47, 99, 100, and 153 were detected at quantifiable amounts in all the participants. PBDE congener 47 made up the largest percentage of quantifiable PBDEs, followed by PBDE 153, 209, 99 and 100.

- Two participants had concentrations of PBDE 28/33 above the CDC average. One of those two were above the CDC 95th percentile. [It should be noted that the LDDI study simultaneously detected PBDE 28/33, while NHANES analyzed only for PBDE 28, creating an inaccurate comparison.]
- Two participants were above the CDC average for PBDE 47. One was above the 95th percentile.
- One participant was above the 95th percentile for PBDE 66.
- One participant was above the 95th percentile for PBDE 85.
- One participant was above the 95th percentile for PBDE 99.
- Two participants were above the CDC average for PBDE 100. One was above the 95th percentile.
- Eight participants were above the CDC average for PBDE 153.
- Eight participants had quantifiable concentrations of PBDE 209. NHANES data are not available for this chemical.

Perchlorate

Six participants had perchlorate exposures above the CDC average 0.066 µg/kg/day, the typical daily dose for the U.S. population.

Perfluorinated compounds (PFCs)

Six PFCs were detected at quantifiable levels in participants. Between two and six PFCs were detected in each participant. Two participants had detectable concentrations of all six PFCs. PFOS and PFOA were found in all participants.

- Three participants were above the CDC average for PFOS.
- Four participants were above the CDC average for PFNA.
- Two participants were above the CDC average for PFOA.
- Seven participants were above the CDC average for PFHxS.

Triclosan

Triclosan was detected in all but one of the participants. It was above the CDC average in six participants and above the 95th percentile in one of those six.

Analytical Methods

Samples were collected and analyzed using the highest quality control and assurance protocols. Analyses of PBDEs, bisphenol A, organochlorine pesticides, and triclosan were performed by AXYS Analytical, a Canadian laboratory that conducts analyses using GC/HRMS (Gas chromatography—high resolution mass spectrometry) and LC/MS/MS (liquid chromatography/mass spectrometry) instrumentation and associated techniques. Mercury and lead analyses were conducted by Brooks-Rand Labs, specializing in analytical services with a focus on ultra-trace level metals analysis and metals speciation. Perchlorate analyses were conducted by the CDC. Details about analytical methods are available upon request.
The Mind, Disrupted project tested twelve participants’ blood, however one participant (David Irons) chose not to have his urine tested, which explains why some charts show all twelve participants and those charts that indicate chemicals tested from urine samples only show eleven participants.

### Mind, Disrupted Participant Results

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Resources

The website www.MindDisrupted.org includes a downloadable copy of this report, fact sheets on each of the chemicals tested for, and other information about the Mind, Disrupted Biomonitoring Project.

Recommended resources

**AAIDD health policy efforts and state outreach**
www.aaidd.org/ehi/content_2375.cfm
AAIDD’s Health Policy efforts, part of the Environmental Health Initiative’s priorities, is focused on educating policymakers at the state and national levels.

**Alaska Community Action on Toxics (ACAT)**
www.akaction.org
ACAT is a statewide organization established in 1997 and dedicated to achieving environmental health and justice. The mission is to assure justice by advocating for environmental and community health. ACAT works to eliminate the production and release of harmful chemicals by industry and military sources; ensure community right-to-know; achieve policies based on the precautionary principle; and support the rights and sovereignty of Indigenous Peoples.

**The Autism Society—Vote4Autism Campaign**
www.autism-society.org/site/PageServer?pagename=vote4autism_home
The Autism Society Vote4Autism Campaign site keeps the public connected to what is going on in the state and federal government. The “Take Action” links let people instantly tell their legislators what they think about legislation that affect people with autism.

**Californians for Pesticide Reform**
Pesticide Biomonitoring Study with Farmworkers in Lindsay, California.

**Centers for Disease Control Biomonitoring Program**
www.cdc.gov/biomonitoring

**CHE — Learning and Developmental Disabilities Initiative (LDDI)**
www.disabilityandenvironment.org
CHE-LDDI hosts an extensive list of resources on learning and developmental disabilities, including fact sheets and practice prevention columns summarizing the science for non-scientists, biomonitoring reports and peer-reviewed summaries of the scientific information regarding environmental influences on LDDs and other neurodevelopmental disorders.

**Collaborative on Health and the Environment (CHE)**
www.healthandenvironment.org
CHE is a collaborative of over 3000 partners, including health professionals, scientists, academicians, and others interested in the most robust science linking environmental threat with health outcomes. CHE maintains a comprehensive listing of environmental health resources, searchable by health issue, environmental/toxic issue and target audience.

**Contaminated without Consent**
www.contaminatedwithoutconsent.org
A 17 minute introductory video on chemical exposure, our health, and how business is responding.

**Commonweal**
www.commonweal.org
Commonweal is a nonprofit health and environmental research institute in Bolinas, California. Commonweal conducts programs that contribute to human and ecosystem health—to a safer world for people and for all life. Commonweal houses the Collaborative on Health and Environment (CHE), the Commonweal Biomonitoring Resource Center, and the Commonweal Cancer Help Program, among other programs.

**Earliest Exposures Biomonitoring Project**
www.watoxics.org/publications/earliest-exposures
Pregnant women tested for chemicals in their bodies by Washington Toxics Coalition and Commonweal.

**The Endocrine Disruption Exchange (TEDX)**
www.endocrinedisruption.com
TEDX, founded by Dr. Theo Colborn, is a non-profit organization dedicated to compiling and disseminating the scientific evidence on the health and environmental problems caused by low-dose exposure to chemicals that interfere with development and function, called endocrine disruptors.

**Environmental Health News**
www.EnvironmentalHealthNews.org
Daily links to top stories in the news about environmental health. This free news service can be subscribed to on the website.
Environmental Justice For All
www.ej4all.org
A 2007 tour of chemically contaminated communities of color and the health effects found there.

Environmental Protection Agency (EPA)
www.epa.gov/TRI
Toxic Release Inventory data to find out what chemicals are contaminating communities in many areas.

Environmental Working Group (EWG)
www.ewg.org
The mission of the Environmental Working Group (EWG) is to use the power of public information to protect public health and the environment. EWG specializes in providing useful resources to consumers while simultaneously pushing for national policy change. Their 2009 study of babies of color cord blood and chemicals can be found at: www.ewg.org/minoritycordblood/home.

Hazardous Chemicals in Health Care
www.psr.org/resources/hazardous-chemicals-in-health.html
This 2009 study by Physicians for Social Responsibility and Clean New York biomonitored physicians, nurses, and health care workers.

Healthy Child Healthy World
www.healthychild.org
Healthy Child Healthy World is leading a movement that educates parents, supports protective policies, and engages communities to make responsible decisions, simple everyday choices, and well-informed lifestyle improvements to create healthy environments where children and families can flourish.

Is It In Us?
www.isitinuse.org
A 2007 biomonitoring project of 35 people in seven states.

Learning Disabilities Association of America (LDA)
www.ldanatl.org/legislative/index.asp
LDA is the leading advocate for laws and policies that create opportunities for people with learning disabilities. This resource includes LDA’s legislative agenda, news from Washington, DC and legislative resources for advocates.

The Louisville Charter for Safer Chemicals
www.louisvillecharter.org
The Louisville Charter provides a roadmap for creating a safe and healthy environment through innovation. The Charter is a living document to guide policymakers toward chemicals policy reform that protects us all. It is endorsed by many labor groups, environmental health and justice organizations.

The National Association of The Dually Diagnosed (NADD)
www.thenadd.org/pages/membership/policy/policies.shtml
NADD maintains a listing of U.S. public policy updates related to learning, developmental, neurological, and mental health problems.

Pesticide Action Network-North America (PANNA)
www.panna.org
Pesticide Action Network North America (PAN North America, or PANNA) works to replace the use of hazardous pesticides with ecologically sound and socially just alternatives. One of five PAN Regional Centers worldwide, this network challenges the global proliferation of pesticides, defends basic rights to health and environmental quality, and works to ensure the transition to a just and viable society.

Program on Reproductive Health and the Environment (PRHE)
http://prhe.ucsf.edu/prhe
The Program on Reproductive Health and the Environment (PRHE) at the University of California in San Francisco (UCSF) is dedicated to creating a healthier environment for human reproduction and development by advancing scientific inquiry, clinical care and health policies that prevent exposures to harmful chemicals in our environment.

Safer Chemicals, Healthy Families
www.saferchemicals.org
Safer Chemicals, Healthy Families is a groundbreaking coalition of diverse groups united by their common concern about toxic chemicals in our homes, places of work, and products we use every day. SCHF is working to reform the nation’s failed toxics chemical law to protect public health and the environment.

Safer States
www.saferstates.com
A network of diverse environmental health coalitions and organizations in 16 states around the country working on state legislation for environmental health protections from chemicals.

United Nations’ POPs Chemicals
www.chem.unep.ch/pops/newlayout/infopopschem.htm
This international body works to regulate Persistent Organic Pollutants (POPs) such as DDT.

United States Government Accountability Office
Report to Congress on Biomonitoring and EPA.
Women’s Voices for the Earth
www.womenandenvironment.org

Women’s Voices for the Earth (WVE) is a national organization that engages women to advocate for the right to live in a health environment. WVE seeks to reduce and ultimately eliminate environmental pollutants that cause health problems for women.

Collaborative on Health and Environment Disease Database

About the CHE Toxicant and Disease Database

The Toxicant and Disease Database was developed in 2005 for the Collaborative on Health and the Environment (CHE), an international partnership working to strengthen the science dialogue on environmental factors impacting human health and to facilitate collaborative efforts to address environmental health concerns. The following information is quoted from the databases’ “About” page.

Because the database focuses primarily on human epidemiological studies and a comprehensive review of animal data was beyond the scope of this project, animal data were included for only a few diseases.

Data for the database were obtained from three major textbooks on the topic of environmental medicine and toxicology. These sources are:


Literature searches for human epidemiological studies and reviews of disease topics were carried out to supplement and update textbook information. Please note the CHE Toxicant and Disease Database is being updated and is expected to be re-released by Fall 2010.

Endnotes


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62 Collaborative of Health and the Environment, CHE Toxicant and Disease Database. Available: www.healthandenvironment.org/tddb/disease/796


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

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

www.minddisrupted.org

Learning and Developmental Disabilities Initiative (LDDI)
Laura Abulafia and Elise Miller
www.disabilityandenvironment.org and www.healthandenvironment.org/working_groups/learning

including LDDI’s Leading Organizational Partners:

[Links to websites and organizations listed in the image]