Pollution, Toxic Chemicals, and Mental Retardation

Framing a National Blueprint for Health Promotion and Disability Prevention

Proceedings of a National Wingspread Summit

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July 22-24, 2003

Summit Sponsors:
- The John Merck Fund
- American Association on Mental Retardation
- The Arc of the United States Research Fund
- Association of University Centers on Disabilities
- The Johnson Foundation

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Acknowledgements

Wingspread was originally a private home, designed by Frank Lloyd Wright in the late 1930s. For 20 years it was a family residence, and since 1960 has served as The Johnson Foundation's educational conference center.

The National Summit participants owe a deep debt of gratitude to the Johnson Foundation and President Boyd H. Gibbons, III for hosting the Summit at their beautiful Wingspread Conference Center in Racine, Wisconsin. We are particularly grateful to Christopher Beem, Program Officer, Democracy and Community, and Family, for herding us through the three packed days with such efficiency, diplomacy, and good humor. While cocooned in the graciousness, warmth, and hospitality of the facility and staff, we were able to concentrate without distraction on the issues before us. For this, we thank them.

We also wish to thank The John Merck Fund and Chairman Francis W. Hatch, and Executive Director Ruth G. Hennig for funding the Summit and follow-up activities. Their financial support, as well as steadfast and enthusiastic interest in this topic have motivated us to continue activities well beyond the Summit itself. None of this would have been possible without their generous support.

"We called it 'Wingspread' because spread its wings it would."
–Frank Lloyd Wright

We also wish to thank M. Doreen Croser, Executive Director of the American Association on Mental Retardation, for spearheading and organizing the Summit. We also thank Steven M. Eidelman, Executive Director, The Arc of the United States, and George Jesien, Executive Director, Association of University Centers on Disabilities for their support of the Summit.

And lastly, we all wish to thank Ansley Bacon, Executive Director, Westchester Institute for Human Development, for acting as conference facilitator for our diverse group.

1. Introduction

Pollution, Toxic Chemicals, and Mental Retardation: A National Summit

CONFERENCE PRESENTERS:
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On July 22-24, 2003, a select group of national leaders in developmental disabilities and environmental health met at the prestigious Wingspread Conference Center in Racine, Wisconsin to forge a new partnership. The partnership was based on a concern for people with developmental disabilities and the effects that toxicants in our environment may have on this vulnerable population, and the role that environmental toxicants play in contributing to mental retardation and developmental disabilities.

The National Summit was the brainchild of M. Doreen Croser, Executive Director of the American Association on Mental Retardation (AAMR), and was sponsored by The John Merck Fund, the American Association on Mental Retardation, The Arc of the United States Research Fund, the Association of University Centers on Disabilities, and The Johnson Foundation.

A select group of national leaders met to forge a new partnership based on a concern for people with developmental disabilities and the role that environmental toxicants play in causing developmental disabilities.

The goal of the Summit was to bring together the developmental disabilities network with the environmental health network to work collaboratively to reduce the occurrence of mental retardation and secondary disabilities caused by environmental pollutants, and to enhance the health of people with developmental disabilities.

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The outcome of the Summit was to begin to frame a National Blueprint for Health Promotion and Disability Prevention aimed at developing strategies for reducing the unnecessary occurrence of disabilities due to the avoidable exposure to pollutants and toxicants.

Participants included representatives of 33 national organizations, government, and service agencies, and included scientists, researchers, health care professionals, administrators, policy

professionals, practitioners, and people with disabilities. The participants gathered over three days, heard nine experts present papers in their topic areas including: 1) orientation to the issues; developmental disabilities and environmental contributors; 2) the latest research findings; and 3) implications for our communities and our lives. After the presentations, participants divided into four Work Groups to react to the presentations and formulate statements that were then shared with the entire group. On the last day of the conference, the participants reconvened to formulate recommendations and achieve consensus on steps that should be taken to advance this agenda: Framing a National Blueprint for Health Promotion and Disability Prevention.

For more information and complete copies of the papers presented, log on to: www.aamr.org/ToxinsandMentalRetardation

The Report

The Executive Summary summarizes key issues and ideas presented at the Wingspread Summit on Pollution, Toxic Chemicals, and Mental Retardation. The report also includes excerpts of the papers presented—including an orientation to mental retardation and developmental disabilities, an orientation to environmental contributors, research findings, community and individual implications, and policy realities. Finally, it includes the framework for a National Blueprint for Health Promotion and Disability Prevention. Appendices contain 1) Work Group recommendations, 2) a list of participants, 3) abbreviations, and 4) a list of resources.

The report, complete copies of the papers (including references and footnotes), plus additional information can be found on the AAMR web site at www.aamr.org/ToxinsandMentalRetardation.

It is our intention that this report will stimulate additional national discussion, expanded research, and policy changes to move this important issue forward. It is our hope that individuals and organizations will join our collaboration to expand and complete a National Blueprint for Health Promotion and Disability Prevention, and to take actions that will reduce the unnecessary occurrence of developmental disabilities caused by environmental pollutants.

2. Executive Summary

The Link Between Mental Retardation and Pollution and Toxic Chemicals

This Executive Summary contains highlights of the information presented and recommendations made at the Summit. Chapter 8 contains a framework for a National Blueprint for Health Promotion and Disability Prevention. The report can also be found online at www.aamr.org/Toxinsand MentalRetardation.

This Executive Summary explains the definition of mental retardation and developmental disabilities, and the nature, source and effects of toxic chemicals on our general health. Finally, the connection between toxic chemicals and mental retardation is examined. While some associations can be made, it is clear that more focused research is needed to link toxic exposures to developmental disabilities. Finally, the Summary highlights key policy and research recommendations made by the Summit participants. A complete list of all recommendations can be found in chapter 8.

Mental Retardation and Developmental Disabilities: Orientation to the Issues

What Is Mental Retardation?

Mental retardation is a disability characterized by significant limitations in intellectual functioning and adaptive behavior. These limitations appear in conceptual, social, and practical adaptive skills. Conceptual skills are things like language, reading and writing, money concepts, and self-direction. Social skills are interpersonal abilities, responsibility, self-esteem, and the ability to follow rules. Practical skills are activities of daily living—eating, dressing, cooking, managing transportation, and using the telephone. Mental retardation originates before age 18 (AAMR definition).

A person with mental retardation has significant limitations in intellectual functioning and adaptive behavior.

Mental retardation (MR) comprises the largest group of individuals with developmental disabilities. Developmental disabilities (DD) refers to a larger group of disabilities—including autism, cerebral palsy, epilepsy, attention deficit disorder, and other neurological

disorders—that also occur during the developmental years (birth–18).

How Prevalent Are Mental Retardation and Developmental Disabilities?

Approximately six million people in the U.S. have mental retardation.

The numbers appear to be growing. Approximately 2 percent, or six million people (including 1.4 million children), in the U.S. have mental retardation. An estimated 12 million children (17 percent) have one or more learning, developmental, or behavioral disability, and these numbers appear to be increasing. Three to eight percent of the four million children born in the U.S. each year (120,000-320,000) have a developmental disability. The diagnosed incidence of brain and nervous system disorders in children has jumped 40 percent from 1973 to 1994. Cases of identified autism have increased ten fold since the 1980s. (Some of these increases may be due to increased reporting and/or changing diagnostic criteria.)

What Causes MR/DD?

Mental retardation can be the result of any one of many factors, or a combination of multiple factors. There are dozens of potential single causes—from chromosomal disorders like Down syndrome and Fragile X syndrome, to infections like meningitis or encephalitis, to environmental influences like fetal alcohol syndrome or fetal exposure to methylmercury. However, as much as 50 percent of all cases of mental retardation have *more than one cause.*

Half of all mental retardation is the result of multiple causes. Half of what used to be called mild mental retardation is the result of unknown causes.

Yet for many, the cause is unknown. Studies that used the older classification systems have shown that approximately 50 percent of the cases of mild mental retardation and 30 percent of the cases of severe mental retardation are due to *unknown causes* (although genetics research may change this in the future). There is no one, single biological marker for mental retardation. Mental retardation is often not diagnosed until later in childhood—often around age 8.

Conditions that may be associated with mental retardation include:
- Epilepsy
- Cerebral palsy
- Low birth weight
- Visual impairment
- Hearing impairment
- Behavioral challenges
- Psychiatric disorders
- Microcephaly
- Macrocephaly

Quality of Life

People with mental retardation may have a wide range of chronic or acute diseases, a shorter life expectancy, and lesser quality of life than the population in general. People with developmental disabilities are often poorer than non-disabled people, but they, too, are living longer than they used to. However, their health is

often more vulnerable, and their access to health care is often more limited than their non-disabled counterparts.

The Economic Costs of MR/DD

The economic costs to society of MR/DD are very difficult to measure. The Centers for Disease Control and Prevention (CDC) estimates lifetime costs in 2003 dollars are expected to total $51.2 billion for people born in the year 2000 with mental retardation. Neurodevelopmental deficits are estimated to cost society anywhere from $82.5–$167 billion per year. Besides the obvious human costs, providing services to people with disabilities is often more expensive than providing the same services to non-disabled individuals. Special education services to all students with disabilities costs $77.3 billion per year (22 percent of the total spent on all children). MR, autism, and cerebral palsy are estimated to generate lifetime costs in the billions of dollars.

The National Academy of Sciences estimated that environmental factors account for 5–20 percent of developmental disabilities, meaning the potential costs due to environmental factors could be anywhere from $4.6–18.4 billion—although these are very rough estimates. The financial impact of secondary disabilities due to additional exposure to environmental toxicants would raise that figure considerably.

In addition, children and youth with disabilities have become increasingly overrepresented in the juvenile justice system due to the lack of adequate intervention and supports necessary to keep them out of the system, thus generating additional service costs.

Pollution and Toxic Chemicals: Orientation to the Environmental Issues

How Many Chemicals Do We Live With?

It seems that we are virtually swimming in a sea of chemicals. We use them to fertilize our lawns, clean our homes, act as flame retardants, keep the bugs off our apples, and help produce plastics and other products favored by American consumers. Chemicals are in our walls, floors, clothing, and cars, and in our blood, urine, and breast milk.

Global chemical use grew from 1 million tons per year in 1930 to 400 million tons per year in 1998.

About 80,000 new synthetic chemicals have been approved for use in the U.S. since World War II. And another

2,000–3,000 new chemicals are registered each year. Global chemical use grew from 1 million tons per year in 1930 to 400 million tons per year in 1998.

But, we are learning that there is a price to pay for chemical abundance and convenience. The air we breathe, the food we eat, and the water we drink are often laden with chemicals that did not exist before the 1940s. Some of these chemicals have been *proven* to cause developmental disabilities; some are *suspected* of contributing to developmental disabilities. Some may contribute to other health problems. But, for the vast majority of chemicals and chemical combinations, we have no idea what effects they could be having on our current and future health, and on the health and development of future generations.

Testing of individual chemicals is deficient; only a few have undergone comprehensive safety assessments. And, *none* of the 15,000 *most commonly used* chemicals have undergone toxicity testing in the combinations in which they actually occur in the marketplace—in other words, how you buy them from your local store. *Remarkably, in America today there is no mandatory testing of chemicals prior to their use for their potential to cause harm, therefore,* when you buy a product off the shelf that contains chemicals, no one—not the government, nor the manufacturer—has evaluated its potential to cause you harm.

None of the 15,000 most commonly used chemicals have been tested for toxicity in the combinations in which you buy them from your local store.

Where Do These Chemicals Come From?

The chemicals surrounding us in our daily lives come to us in two main ways: through consumer products and through environmental releases (pollution) into air, soil, and water.

Toxic chemicals can be found in different categories of chemicals, including:
- Industrial chemicals
- Pesticides
- Fertilizers
- Pharmaceuticals

Products

Chemicals that may be toxic can be used in our consumer products because they are essential to the intended purpose of the product, or because they enhance the product in some way, or because they are less expensive than a less harmful alternative. Chemicals that may be toxic can also be unintentionally included in products because they are by-products of the manufacturing process.

Pollution

Toxic chemicals that are a byproduct of the manufacturing process can also be released into the air, water, or soil, and can pose a potential danger. In 2001, U.S. industries discharged 6.2 billion pounds of toxic chemicals directly into our water, land, and air,

U.S. industries discharged 26.7 billion pounds of toxic waste in 2001.

and generated 26.7 billion pounds of toxic waste. (These figures include fewer than 700 chemicals in the industries for which pollution reporting is required, and only the *major* emitters—not small emitters/generators.) While it may not be possible to eliminate all toxicants from the manufacturing processes, it is possible to limit their emissions into our air, water, and food supplies.

The Connection between Toxic Chemicals and Health

Can These Chemicals Cause Harm?

Many toxic chemicals migrate easily through the air and water. Some can enter our bodies when we breathe, eat, and drink. Some toxicants are persistent, cumulative, and do not naturally degrade or break down in the environment. These can be present in our drinking water, and can accumulate in fruits and vegetables, in the fatty tissues of cows, chickens, and fish—and be transferred to humans via the food supply. Some—like lead—are never eliminated, but bioaccumulate in our bodies. We are also exposed to some toxicants through products that contain harmful chemicals. These toxic chemicals can contribute to a myriad of health problems large and small—from slight nausea at school, to permanent developmental disabilities, asthma, birth defects, and cancer.

Toxicity is determined by the toxicant, amount, duration, and timing.

Many chemicals are generally safe at expected levels of exposure and add to our quality of life. But others are harmful. The harmful effects are often determined by the *kind* of toxicant, the *amount* of the toxicant, the *duration* of the exposure, and the *timing of the exposure*—when in the developmental process exposure occurs.

Neurotoxicants

Toxic means the chemical is poison or harmful. Neurotoxic means the chemical is harmful to the brain and nervous system.

According to the Office of Technology Assessment, between 3–5 percent of all non-pesticide chemicals, or roughly 2,400 to 4,000, are neurotoxicants—toxicants that affect the entire nervous system, especially brain development. In 1997, nearly 75 percent of the top 20 toxic chemicals released by large U.S. industrial facilities were *known or suspected neurotoxicants*—1.2 billion pounds worth.

ENVIRONMENT =
BIOLOGICAL FACTORS
(diet/nutrition, physical health, infectious agents)
+ PHYSICAL FACTORS
(chemical agents/toxicants, radiation, noise)
+ PSYCHOSOCIAL FACTORS
(environmental status, stress, education).

TOXICANTS HIJACK THE DEVELOPMENTAL PROCESS

Recent research shows that environmental factors (like nutrition or exposure to environmental toxicants) can actually *change* gene expression. In other words the environment, and thus environmental toxicants, can actually change the ways genes work, and change who we become and how we function.

Hormones are instrumental in turning genes on and off by binding with receptors at the molecular level. In one animal study, chromosomal abnormalities (aneuploidy) were created by exposure to bisphenol-A, found in some plastic toys and baby bottles. Various studies show that bisphenol-A can act like the hormone estrogen. Among other consequences, because of this estrogenic activity, bisphenol-A can alter brain development in experimental animals.

Toxicants can work by hijacking the developmental process. Lower doses can be harmful. Combinations of chemicals must be considered. Timing is crucial.

This and other new research has caused us to think about toxic chemicals in a whole new way. We used to think that toxicants worked by overpowering the body's defenses or directly damaging cells. Now we know that toxicants can also work by hijacking or controlling the developmental process. We used to think that only high doses mattered; now we know that doses previously considered "acceptable" can have harmful impacts. We used to look at chemicals individually; now we know that we must consider combinations of chemicals as they appear in the environment.

WINDOWS OF VULNERABILITY

We used to think that the amount or dose of a toxicant alone determined the effects on our health. However, recent research suggests that it is both the dose *and* the timing—when in a person's life exposure to the toxicant occurs—that are important. Exposures to some chemicals even at low doses during particularly vulnerable developmental windows in fetuses and young children can contribute to a range of health problems.

Environmental toxicants can cause permanent genetic changes and developmental disabilities

Healthy brain development depends on a tightly orchestrated series of events. Brain cells proliferate, migrate, differentiate, and establish connections with other cells to form complex neuronal circuits. Disruption of this sequence at any point can have a lasting impact on how the brain functions later in life.

Brain development is controlled by genetic and environmental factors that interact with each other in complex ways. Environmental factors (chemicals, drugs, alcohol, nutrition) can alter the signaling chemicals that control brain development. These signaling chemicals can also alter or modify the expression of genes. Environmental toxicants can cause permanent genetic changes and developmental disabilities.

Where Can These Chemicals Be Found?

They Can Be Found in Us

The CDC says we all carry chemicals—potentially hundreds—in our bodies. Many of these did not exist 60 years ago. This is our "body burden" of chemicals. We now know that young children routinely carry detectable levels of lead, mercury, PCBs, dioxins, flame retardants, and certain pesticides, among other neurotoxicants. Known or suspected neurotoxicants travel across the placenta, and are found in newborns, indicating in utero exposure. Breast milk has also been shown to be contaminated with many such compounds. Almost 8 percent (5 million) of women of childbearing age carry blood mercury concentrations sufficient to create a risk of cognitive and developmental disabilities in the fetus.

The average American carries a "body burden" of hundreds of created chemicals that did not exist 60 years ago.

They Can Be Found in Our Homes

Some consumer products like paints, varnishes, solvents, pesticides, cleaning products, new carpets, plastics, upholstered furniture, or electronics can contain chemicals that can cause harm. Some toxic chemicals can be contained in products made in foreign countries that have fewer laws and regulations.

Lead

The most well-known brain toxicant found in our homes is lead. Lead in high doses can produce serious neurological damage, including cerebral palsy and mental retardation. It has been discovered that children exposed to lead have a higher likelihood of developing delinquent behavior resulting in contact with the juvenile justice system. Even low blood lead levels (below 10 μg/dl) may result in lowering IQ test scores and other health problems.

Added to house paint until 1978, lead continues to be found in the paint used on some plastic bread bags, in calcium supplements, in

children's toys, in decaying Venetian blinds and other common household products. In the United States, lead has been banned from pencils, crayons, and chalk, but continues to be found in some of these items that are manufactured abroad, but imported to the U.S.

While lead remains a serious public health problem, it is an example of how much can be achieved with a concerted cooperative effort among the public, industry, and the government. Major reductions in average lead blood levels were achieved by removing lead from gasoline. The number of children with dangerous levels of lead in their blood has declined over the past thirty years due to this partial banning of lead and routine screening of children. The number of households with lead-based paint has been reduced 41 percent since 1990.

However, there are still 1.2 million low-income homes with children under six years of age containing lead, and only one-third of all children are screened for lead levels. Minority children, who are over-represented among the poor, continue to carry a higher lead body burden than white children.

Flame Retardants (PBDEs)

Many furniture cushions, textiles, and electronics products contain PBDEs (polybrominated diphenyl ethers), which are often used as a flame retardant—despite the availability of safer alternatives. By routes not completely understood, PBDEs are found in sewage, fish, human bodies, and breast milk. Chemically, PBDEs look very similar to PCBs (polychlorinated biphenols). Animal tests show that PBDEs can damage the brain during development and cause thyroid problems, hyperactivity, memory impairment, and learning disabilities.

Alcohol and Toluene

Alcohol has long been pervasive in our society. Studies show that women who drink alcohol while pregnant can cause permanent neurological damage in their children. Even relatively low levels of alcohol exposure, or single high peaks of exposure at critical times during pregnancy can impair brain development in the fetus, leading in some cases to fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE). Prolonged or high levels of exposure to alcohol can cause mental retardation.

Toluene, like alcohol, is an organic solvent found in household products. Large maternal exposure to toluene during pregnancy can produce children with fetal solvent syndrome that resembles fetal alcohol syndrome.

Tobacco Smoke and Other Indoor Air Pollutants

Tobacco smoke, dust, dust mites, molds, pets, and roaches found in homes can all be harmful to general health. Tobacco smoke can be harmful to brain development at certain times and doses of exposure. The good news is that levels of continine (nicotine) are dropping for all age groups. Unfortunately, in the year 2000, levels in children were more than twice that of adults. African Americans had levels more than twice those of Hispanics and whites.

They Can Be Found in Our Children's Toys

Phthalates

Some children's toys, plastic water bottles, soap, shampoo, and medical devices contain phthalates ('tha-lates'). Phthalates have been linked as having a developmental impact on the reproductive systems in animal studies.

Bisphenol-A

Bisphenol-A is a component in many plastics that can be found around the house, like plastic baby bottles, food containers, and linings in metal food cans. Although the data are incomplete, in animal studies bisphenol-A has been associated with cancer, endocrine-related health conditions, and a chromosome defect associated with Down syndrome. Often people wash their plastic toys and baby bottles in bleach to clean them. The interaction of some of these household bleaches and some plastics containing bisphenol-A can cause the bisphenol-A to leach out of the products. Chewing can also release bisphenol-A from plastics.

Do you know that in the U.S. today you can buy a teething ring that contains cadmium and other toxicants harmful to your baby?

They Can Be Found in Our Food

Some of the food we buy contains pesticide residues and other pollutants. Some micronutrient fertilizers contain heavy metals and dioxins that come from the "recycling" of hazardous industrial waste.

Meat Contains PCBs

Polychlorinated biphenols (PCBs) can be found in the fat of some fish, beef, pork, dairy products, processed food, breast milk, and elsewhere in the environment. PCBs are particularly toxic to the brain. Exposure early in life when the brain is still developing can lead to IQ loss and changes in learning and behavior. High doses

can produce serious neurological damage including cerebral palsy and mental retardation.

Around 70 percent of the mercury in the environment comes from coal-fired electric power plants and waste dumps. Increases in emissions over the past 100 years have tripled mercury pollution. *In these large amounts, mercury remains in the environment indefinitely.*

Fish Contain Mercury, PCBs, and Dioxins

Despite the health benefits of eating fish, some fish have been found to contain mercury, PCBs, dioxins, flame retardants, and other toxic chemicals. Fish is the major source of human exposure to methylmercury, the form of mercury that is most hazardous to the developing brain of fetuses, infants, and children. Larger predatory fish—like tuna, shark, swordfish, tilefish, and mackerel—tend to have higher mercury levels. Large fatty fish, tend to have high levels of lipophilic (fat-friendly) toxins, and are also an important source of PCBs, flame retardants, and dioxin exposures.

Mercury is emitted into the air, deposited on the surface of the water, eaten by microorganisms, which are eaten by small fish, which are then eaten by larger fish.

Mercury is toxic to the brain. Exposure early in life when the brain is still developing can lead to IQ loss and changes in learning and behavior, depending on the size and timing of the exposure. High dose exposure prenatally can produce serious neurological damage, including cerebral palsy and mental retardation. Exposure to lower doses may cause subtle neurodevelopmental effects on attention, memory, and language skills.

Vegetables, Grains, and Meat Contain Lead, Cadmium, Chromium, and Dioxin

Lead arsenate, used as a common pesticide for decades, can be taken up from the soil into root vegetables. Dioxins, lead, and mercury, found in some soil, have been linked to infertility, birth defects, and neurological system abnormalities. Because many chemicals bioaccumulate in fatty tissue, they are often found in higher quantities in food products, beef, and poultry, as they move up the food chain.

Heavy Metals Are:
- Lead
- Mercury
- Cadmium
- Chromium
- Arsenic

Heavy metals and other chemicals that are present in industrial hazardous waste can legally be "recycled" into fertilizer products, ostensibly as essential micronutrients. This waste comes from mining, steel mills, and other industries.

Breast Milk Contains Lead

Breastfeeding, the most intimate act between a mother and child, can be a source of potentially harmful chemicals (though breastfeeding remains preferable to formula feeding because of the many known benefits of breastfeeding for the developing infant). Lead stored in a mother's bones is released into her bloodstream and her milk. Breast milk has been found to contain other toxicants as well, such as mercury and PCBs.

They Can Be Found in Our Schools

We think our children are safe when they are in school. Yet, more than one-third of America's public schools need major repairs or replacement; about one-quarter have unsatisfactory ventilation, poor indoor air quality, and poor heating, acoustics, and noise control. According to the Environmental Protection Agency (EPA), indoor air is 5 to 100 times more polluted than outdoor air, and is a top human health hazard. School classrooms with poor indoor air quality make it much more difficult to think clearly and concentrate, thus impeding learning. Cancer, developmental delays, learning disabilities, asthma, dizziness, and vision problems have all been linked to poor school environments. Asthma accounts for an estimated 10 million missed school days.

They Can Be Found in Our Workplaces

The type of work we do and where we do it determines the kind and amount of exposures we will have to toxic chemicals. But, while we may be safe, our children may not. Some studies have shown that children whose parents work with pesticides and wood preservatives have more birth defects. Children born to parents who use certain chemicals at work are more likely to have cancer in childhood. Children of women exposed to chlorinated solvents have an increased risk for heart and oral cleft defects. Studies demonstrate that shoes track toxic chemicals into the home, where they can persist, sometimes for years, in carpets and dust. Work clothes can transfer toxic chemicals to other clothes in the family wash where even multiple washings may not remove them.

Some People Are Especially Vulnerable

Infants and Children

Fetuses are especially vulnerable to toxicants and neurotoxicants because their brains and central nervous systems are developing. As previously stated, the effects of these toxicants depend on the kind, the amount, the duration of exposure of the toxicant, and the timing, or when the toxicant exposure occurs during the fetus's development.

Children ingest half of their lifetime pesticide intake—mostly through food—by the age of five.

Children are particularly at risk because: 1) their bodies and neurological systems are still developing; 2) they eat, drink, and breathe more per pound of body weight than adults (seven times more water and twice as much air); 3) they can be exposed to more

environmental threats as a result of behaviors like crawling on carpets; and 4) they are more susceptible to many environmental hazards. Children ingest half of their lifetime pesticide intake—mostly through food—by the age of five. In addition, their endocrine, neurological, hormonal, and immune systems are still developing well into their teenage years and exposures to some chemicals at certain times can compromise those systems for a lifetime.

Are People with Mental Retardation and Developmental Disabilities More Vulnerable?

Although much more research is needed, there is concern that some people with developmental disabilities may be more susceptible to the effects of toxicants than their non-disabled peers because of secondary physical problems. (For instance, people with Rhett syndrome often have breathing difficulties. This condition is exacerbated by the affects of toxicants in the air.) Children with mental retardation engage in many of the same behaviors as other children, like crawling and chewing on objects—however, they may do so for longer periods of time—and that puts them at greater risk. There is concern that even small amounts of neurotoxicants—such as lead and pesticides—might have a significant negative impact on the health of a person with existing neurological disabilities further impacting their capacity to learn, talk, read, calculate, memorize, conceptualize, organize, and/or behave appropriately.

Is Our Government Protecting Us?

Many people believe 1) that toxicants in their products or the environment do not pose a significant health risk, 2) that if the chemicals in products were really harmful, the government wouldn't allow them to be sold, and 3) that federal laws require extensive safety testing before a chemical product can be sold. None of these is true.

In fact, the government has or takes very little control over the safety of products sold. In some circumstances, even when they know a product is likely to pose a significant risk, the EPA or other agency may not be able to act because the laws and regulations under which they operate do not provide enough authority to act. When the EPA proposed banning asbestos, a known carcinogen, a federal judge concluded that, according to the

When the EPA proposed banning asbestos, a federal judge concluded that EPA did not have sufficient statutory authority to ban its use.

statute, the EPA did not have sufficient legal authority to ban its use. In other cases, the agency may simply decline to utilize the authority that it has.

No Testing Required

With the exception of pesticides and pharmaceuticals, chemical manufacturers are not required to assess the potential health impacts of their products. Chemicals are generally assumed safe until proven otherwise. Consequently, the burden of assessing safety or "proving" harm often falls to the public.

There are many known toxicants with probable links to cancer, birth defects, or the ability to reproduce; many more are suspected neurotoxicants. *Only 15 chemicals* have undergone comprehensive neurodevelopmental testing.

Organophosphate pesticides (OPs) are specifically designed to be toxic to the brains and nervous systems of insects and pests. However, the EPA does not require that these OP pesticides—that are used on our foods—be tested for toxicity to *our* brains or nervous systems. There are also no federal regulations requiring testing of fertilizers for heavy metals, dioxin, or other pollutants.

Little Testing, Little Follow Through

Under a 1984 law, under some circumstances regulators can require toxicity testing when a chemical is first registered with the EPA. However, most chemicals are not tested. In addition, the toxicity testing guidelines for pesticides used on food were last revised 20 years ago. Although EPA has repeatedly started to revise these regulations, they have repeatedly failed to bring the revisions forward.

Because of the large volume of *new* chemicals registered every year (2,000–3,000), the EPA has concentrated on these newer chemicals, rather than going back to review older chemicals. As of the year 2000, the toxicity of many pesticides registered *prior to 1984* (including most OP neurotoxicants) still had not been reviewed. These "old" pesticides represent the biggest problem. Therefore, some decades-old neurotoxic OP insecticides remain in widespread use even though EPA has acknowledged that the manufacturers have failed to submit all the required tests for neurotoxicity.

The Consumer Product Safety Commission (CPSC) decided to allow phthalates in children's toys because they decided the risk was "acceptable."

Even when there is credible evidence that harm may occur, regulators try to "manage" the risk, rather than avoid it. Because chemicals are assumed safe until proven unsafe, and because

testing and monitoring requirements are so ineffective, regulators have to first spend years trying to estimate the odds that a chemical *may* produce a negative health risk. After they determine it *may*, regulators then attempt to keep the risk to an "acceptable" level.

The Connection between Toxic Chemicals and Mental Retardation

What Do We Know? What Don't We Know?

So, what do we know and what don't we know about toxic chemicals and their possible connection to mental retardation and developmental disabilities?

We know that more toxic chemicals are being put into our environment every year.

We know that our chemical body burden for some chemicals is increasing.

We know that some neurotoxicants can affect brain and nervous system development in our children.

We know that the developing brain is uniquely vulnerable to toxic chemical exposures.

Mental retardation is defined as significant limitations in intellectual functioning and adaptive behavior (language, reading, dressing, cooking) that occurs before age 18.

We know that a large percentage of occurrences of mental retardation are likely to have more than a single cause and that several causes can interact including genetics, infections, chemical toxicants, birth and other trauma, and hormonal factors.

We do *not* know the extent to which neurotoxicants may be implicated in causing mental retardation.
Because of the necessary restrictions on human testing, most of the limited testing of chemicals is done on laboratory animals, and there are no good animal models for testing mental retardation.

We know that fetal exposure to *larger levels* of neurotoxicants—alcohol and other solvents, PCBs, and heavy metals (mercury and lead)—*can result in mental retardation* and other neurodevelopmental disorders.

We know that exposure levels that were formerly considered to be "safe" for lead, mercury, and PCBs,

have since been proven to disrupt normal brain development, and that because of these new studies, safe exposure levels have been revised downward.

Signs of impaired brain development include hyperactivity, learning and memory disorders, or behavioral abnormalities.

We know that exposure to several *known* environmental neurotoxins (such as lead, mercury, PCBs, and solvents such as alcohol and toluene, and tobacco smoke) can disrupt human brain development, and, depending on the dose, result in permanent limitations in intelligence, learning, attention, memory, comprehension, language acquisition, written and verbal communications, behavior, and socialization skills—some attributes of developmental disabilities. Early life exposure to additional chemical toxicants (some pesticides, solvents, and other heavy metals) is also suspected of disrupting brain development.

We know that timing is important, that exposure to neurotoxicants during key vulnerable periods of brain development at levels that do not impact adults can cause permanent, unrecoverable neurodevelopmental limitations later in life. And we know that the fetal brain may be susceptible to some neurotoxic exposures that do not have comparable effects postnatally at similar dosages.

We know that childhood brain and nervous system cancers have been steadily increasing, and that autism, learning, behavioral, and developmental disabilities are likely to be increasing.

So What Are We to Do?

Given that developmental disabilities appear to be increasing, and that more chemicals that could impact brain development are being manufactured and put in the marketplace each year, environmental exposures are likely to be a significant reason we are seeing the numbers of neurological problems we are today. That is why we need to increase research in this area. We also need to learn more about how neurotoxicants may contribute to mental retardation relative to various learning disabilities or autism. In the meanwhile, the apparent increases in the incidence of learning and developmental disabilities are already being played out in real world terms. Preventing any kind of neurologically based disability must to be a priority if we are to have a healthy society.

A partnership of government, industry, and the public can take positive steps in making our air, water, soil, food, and products safer. Such a partnership could also improve the health of all Americans, and may help prevent some developmental disabilities. Wingspread Summit participants identified and prioritized steps that should be taken toward this goal. Below are highlights of some of the recommendations. See chapter 8 for a complete list of recommendations.

1. Include People with MR/DD

People with disabilities and their caregivers have a right to be involved in designing and participating in research studies and policy decisions that affect their lives.

2. More Effective Laws and Regulations Are Needed

Stronger laws and regulations are needed to ensure public health. At a minimum, the public should have the right to know about any chemicals in their food, products, air, water, and soil that pose a potential threat to their health.

We need more and better regulation of the chemicals contained in the products we buy, the food we eat, and in the environment that surrounds us.

THE EUROPEAN MODEL would set a deadline for companies to provide toxicity assessments on 30,000 chemicals, and to require the manufacturers to apply for permission to use chemicals of "high concern." This also may apply to U.S. chemicals and products being exported to Europe. We may be in the position of having the Europeans set the international standard.

More testing of new toxic chemicals should be required to determine their potential health threat before being put on the market.

The federal and state governments should prohibit the use of a chemical if there is evidence that it poses a serious threat.

The federal and state government should require manufacturers to use safer alternatives where they exist.

The federal and state government should make policy decisions about chemicals based on protecting public health: decisions should be based on the toxicity of a chemical rather than the odds of exposure.

People have a right to know what is in the products they use. We need better labeling laws that would help people with disabilities and all people make informed product choices.

3. More Research Is Needed

Research is increasingly indicating that known and suspected neurotoxicants can influence brain development in ways that can lead to disabilities. Although research alone cannot reduce toxic exposures, it can help us understand the exact mechanisms by which neurotoxins affect brain development.

We need more systematic research and evaluation of a whole host of potentially neurotoxic agents to which people are regularly exposed, focusing on their impact on neurodevelopment.

The EPA/HHS Task Force on Environmental Health and Safety Risks to Children has undertaken the National Children's Study that will follow about 100,000 children before birth, up to adulthood to investigate the relationships between environmental exposures and potential health effects. This study should include children with MR/DD.

We need to research the effects of real-world combined chemical mixtures in products.

We need to conduct more longitudinal studies to gather long-term human data on the effects of specific neurotoxicants on human growth and brain development.

We must research the association between exposure to toxicants and their contribution to causing developmental disabilities.

We must research how toxicants may impact people with MR/DD differently than others due to the suspected potential for greater sensitivities.

Conclusion

The Wingspread summit participants are pleased to have been a part of this important, groundbreaking summit and they are looking forward to educating others about these critically important issues. They encourage other interested individuals, groups and organizations to join our environmental health collaboration in moving this ambitious disability research, policy, and service agenda forward.

3. Orientation to the Issues: Mental Retardation and Developmental Disabilities

Paper 1

MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES: INSIDE LOOKING OUT

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The National Summit provided an opportunity for the environmental health community and the developmental disabilities community to share ideas about the impact of the environment on individuals with mental retardation. Each group brought to the summit unique experiences and a common mission to improve the quality of life for people with mental retardation and related disabilities.

This paper provided an overview of recent findings in the developmental disabilities community that helped participants understand the current issues facing individuals with MR/DD and made suggestions for the future.

What Is a Developmental Disability?

Developmental disability is not a specific medical definition. The term DD covers a heterogeneous group of individuals with disabilities. Mental retardation, cerebral palsy, autism, epilepsy, significant learning disabilities, and other neurological conditions that begin in childhood fall under the umbrella of developmental disabilities.

The definition of developmental disability has evolved from federal and state laws. The latest federal definition is from the Developmental Disabilities Act of 2000 which defines DD as a severe, chronic disability that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age twenty-two;

- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living/ and economic self-sufficiency; and
- reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services/individualized support and other forms of assistance that are lifelong or of extended duration and are individually planned and coordinated.

What Is Mental Retardation?

Mental retardation comprises the largest group of individuals with developmental disabilities. AAMR has had responsibility for defining mental retardation since 1921. The latest update of the definition was completed in 2002.

Mental retardation comprises the largest group of individuals with developmental disabilities.

AAMR Definition of Mental Retardation:
Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

Demographics

Developmental disorders, including autism and attention deficit disorder, are widespread in the U.S. Approximately 6 million people have mental retardation. An additional 3–8 percent of the four million children born each year have one or more developmental disabilities. But once these individuals are grown and out of the educational system, they are hard to identify and track. The importance of the research needed to evaluate the impact of environmental toxicants on individuals with mild mental retardation must be balanced against an individual's right to not be labeled.

Developmental disabilities affect 120,000 to 320,000 new children born each year.

People with Developmental Disabilities Are Living Longer

Approximately 526,000 adults with developmental disabilities 60 years of age or older live in the United States. Life expectancy within the United States has increased over the last century and for people with disabilities is now 67 years for women and 63 years for men (compared with 79.5 years for women and men 73 years for men in the general population). Individuals with severe disabilities tend to have shorter life expectancies. *Increased longevity creates another area for additional evaluation and research.*

People with Developmental Disabilities Are More Diverse than They Used to Be

Racial and ethnic minorities will be in the majority in the coming years. Health disparities of minority populations are compounded when a person also has a disability. *Research on the impact of environmental toxicants and pollution for people with disabilities needs to evaluate race and ethnicity as additional variables.*

People with Developmental Disabilities Are Often Poorer.

The association of poverty with disabilities needs to be addressed. The differences in rates of disabilities among different racial and ethnic groups appears directly related to poverty. *The increased risks of environmental toxicants and pollution in lower socioeconomic groups, as it relates to developmental disabilities, requires further study.*

Findings and recommendations from recent MR/DD conferences can be found in Dr. White-Scott's paper on the website at www.aamr.org/ToxinsandMentalRetardation.

Environmental Issues and MR/DD

Environmental issues impact all segments of the population including individuals with MR. Most research and clinical effort has been focused on the early stages of development from pregnancy through early childhood. There is a need for continued attention for prevention and increased awareness of health promotion across the lifespan. Health promotion and the impact of environmental toxicants and pollution take on an increased importance with the aging of the general population. This trend is also reflected in the MR/DD community.

More Research Needed

There has been little attention paid to the impact of pollution and toxic chemicals on individuals with MR and related disorders. The complex interactions of environment, genetics, and disabilities in today's constantly changing world reflect the ongoing need for additional research of the impact—long- and short-term—of environmental toxicants on developmental disabilities throughout the lifespan.

Financial Impact

The study of environmental pollutants and disease in American children provides estimates of morbidity, mortality, and costs for lead poisoning, asthma, cancer, and developmental disabilities. Estimates of the cost for MR, autism, and cerebral palsy not attributable to lead generate lifetime costs of $92 billion dollars per annual cohort. If the attributable costs due to environmental factors are 5–20 percent, costs could range from $4.6–$18.4 billion. The financial impact of aging and secondary disabilities due to additional exposure to environmental toxicants and pollution requires further research.

The complex interactions of environment, genetics, and disabilities reflect the need for more research of the impact of environmental toxicants on developmental disabilities throughout the lifespan.

Summary

Individuals with MR and related disabilities need to have information to make informed decisions and live a healthy life. The barriers to health care and limited research are major deficiencies in making healthy choices. The impact of pollution and environmental toxicants across the lifespan is an area for collaboration between the disability and the environmental health network. The environmental pediatrics and public health approach is a model for addressing issues of environmental impact across the lifespan. Involvement of self-advocates, family members, policy makers, clinicians, and researchers provide an opportunity for sharing across networks.

Recommendations

The recommendations from recent conferences within the disabilities network give a framework for recommendations in policy, research and practice for environmental issues. It is important to open a dialogue, share ideas, and form action steps that will enhance the quality of life for individuals with developmental disabilities.

Policy Recommendations

Public policy should reflect the increasing awareness of all individuals with developmental disabilities to live active, healthy lives in our society. Environmental health policy should recognize

the full inclusion of individuals with developmental disabilities across their lifespans.

Research Recommendations

Research is needed to identify the impact of environmental toxicants and pollution across the lifespan. People with disabilities and family members must be involved in all aspects of research from inception to dissemination. Research findings must go beyond the researchers to help improve the awareness of the impact of environmental toxicants and enhance the quality of life.

Practice Recommendations

Current practice in health promotion and prevention requires increased activities that are targeted to people with developmental disabilities to minimize or eliminate the impact of environmental toxicants.

4. Orientation to the Issues: Environmental Contributors to Developmental Disabilities

Paper 2

POTENTIAL ENVIRONMENTAL CONTRIBUTORS TO DEVELOPMENTAL DISABILITIES: WHY WE SHOULD CARE

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What Is Environmental Health?

Environmental health refers to any health impact environmental exposures may have on adults and children, starting as early as fetal development. These environmental exposures can come through our air, water, and food. For example, toxic exposures may emanate from industrial or medical waste incinerators, chemical fertilizers on our lawns, insecticides in our homes, lead-based paint on our walls, and endocrine-disrupting chemicals and carcinogens in our personal care products. We can also be exposed to various toxics found in building materials in our homes, schools, hospitals, and offices, as well as in breast milk itself. Recent studies suggest that the health impacts of these exposures may include asthma, birth defects, hypospadias, behavioral disorders, learning and developmental disabilities, various cancers, impaired immune and neurological systems, and reproductive disorders.

Environmental health is also inextricably linked to many other social, environmental, and economic factors. Disparities in exposure to hazardous air pollutants and contaminated drinking water and soil are associated with race and/or economic class because minorities and low-income families often live closer to industrial sites or more polluted areas where land and housing costs are lower. In addition, since the health of humans is inextricably connected to the overall health of our ecological systems— including the health of all other species and the health of forests, prairies, wetlands, rivers, lakes, and oceans—environmental health is ultimately about the health of our planet.

Minorities and low-income families often live closer to polluted industrial sites where housing costs are lower.

Why Is This More of a Problem Now?

Since the petrochemical industry started around World War II, about 80,000 new synthetic chemicals have been approved for use. Of the 15,000 most commonly found chemicals, the vast majority have not been tested individually for human health impacts and none of them have been tested in combination. Each year about 1,500 new chemicals are introduced. Because some of these chemicals bioaccumulate in fatty tissue, they may be found in higher quantities in dairy and meat products. Many of these chemicals migrate easily through the air and water and through the globalized consumer market. For example, chemicals such as DDT, which was banned in the U.S. years ago, still persist in our environment and in our bodies here in the U.S. and continue to reach us through foods we may import from developing countries where these pesticides are still used.

Since around World War II, about 80,000 new synthetic chemicals have been approved for use.

None of the 15,000 most commonly found chemicals have been tested in combinations in which they actually occur in the marketplace.

Some of these synthetic chemicals are also passed on from pregnant mother to fetus and through breast milk to nursing infant. Recent research studies suggest that exposures to specific chemicals at certain doses during particular developmental windows in fetuses and young children may contribute to a range of health concerns. Some health concerns may show up immediately, and others may not become evident until later in life. This is believed to be the case with some reproductive disorders and cancers.

No one is immune from these toxic exposures. Industrialized and non-industrialized populations, adults and children, wealthy and poor, we are all subject to [toxic] exposures in the air, water and food supplies. The Centers for Disease Control (CDC) released two reports over the last couple years demonstrating that we all carry chemicals, potentially hundreds of chemicals, in our bodies that did not exist 60 to70 years ago. We are only beginning to understand the implications for long-term health.

The CDC says we all carry chemicals—potentially hundreds—in our bodies that did not exist 60 years ago.

Why Children Are Particularly Susceptible

Children eat, breathe, and drink far more than adults in proportion to their body weight. For example, they drink seven times more water and take in twice as much air than adults on average. They also ingest half of their lifetime pesticide intake, mostly through food, by the age of five.

Children behave differently from adults. They spend more time on the ground—on carpets, lawns, and floors that may have been treated with pesticides or other synthetic chemicals. Plus, they have many more hand-to-mouth transfers and touch objects and surfaces more frequently without washing their hands thereby increasing their exposures. Many of their biological systems—endocrine, neurological, hormonal, and immune—are still developing well into their teenage years, and exposures to some of these chemicals at certain developmental windows can compromise those systems for a lifetime.

Children drink seven times more water and breathe twice as much air as adults. They also ingest half of their lifetime pesticide intake by age five—mostly through food.

Do Adults Need to Be Concerned about Exposures as Well?

Chemical exposures may not impact adults in the same way as children, but adults' health can also be compromised by environmental toxicants. Even adults without any other health issues may respond negatively to certain exposures, and those with existing conditions may find their health problems are exacerbated. For example, some scientists, such as Bernard Weiss, PhD at the University of Rochester, have suggested that if even small amounts of neurotoxicants such as lead and pesticides get into the systems of those with neurological disabilities, these chemicals could have significant health impacts. Some of these impacts may include the capacity to learn, talk, read, calculate, memorize, conceptualize, organize, pay attention, interact socially, and/or behave appropriately.

Exposures may also induce certain health conditions that otherwise may not have occurred. A few years ago an environmental health researcher offered a helpful analogy: "genes load the gun, and the environment pulls the trigger." In other words, a person may

"Genes load the gun, and the environment pulls the trigger."

have a genetic propensity for a health condition like asthma, but it is not until they are exposed to particular toxicants that their asthma is actually triggered.

Women of childbearing years need to be particularly conscious about what they take into their bodies because these chemicals may be passed on to their children in utero and through breastfeeding. Research to date suggests that in utero exposures are likely to be more highly associated with harm, particularly if they occur at specific developmental windows. However, even though scientists have found that a mother releases some of her toxic "body burden" by breastfeeding, breastfeeding is still superior to formula feeding for a variety of reasons.

Why Should We Care About These Toxicants in Relation to Developmental Disabilities?

Given how complex our biological systems are and the fact that brain development is influenced by heredity, genetic, social, and environmental factors and the interactions among them, we do not know yet exactly *how* these toxics may be implicated in the manifestation of mental retardation and other developmental disabilities. In addition, research in this area is still quite nascent, so inevitably some of the findings have conflicting results that will need to be clarified through further studies.

We do not know exactly how toxicants may be implicated in the manifestation of mental retardation. But definitive research shows that some toxicants can disrupt brain development and cause permanent damage to intelligence, learning, memory, behavior, and comprehension.

Negative Effects on Development

That said, definitive research shows environmental factors such as lead, mercury, polychlorinated biphenyls (PCBs), alcohol, toluene, and tobacco smoke are capable of disrupting human brain development. This disruption, in turn, can result in permanent, negative impacts on intelligence, learning, attention, memory, comprehension, language acquisition, written and verbal communications, behavior, and socialization—some of which are considered attributes of developmental disabilities. Additional environmental chemicals and pollutants, such as some pesticides, solvents, and other heavy metals have been shown to disrupt brain

Childhood brain and nervous system cancers have jumped 40 percent; autism has increase 10 times, and learning, behavioral, and developmental disabilities are increasing.

development in animal studies and are suspected of having similar effects in humans.

In this context, a few statistics:

- Incidence of childhood brain and nervous system cancers jumped 1.8 percent per year, or 40 percent from 1973 to 1994.
- Autism spectrum disorder is estimated to affect 450,000 children under the age of 18 and it appears to be 10 times more prevalent today than it was in the 1980s (although some increase could be due to changes in diagnostic criteria).

- An estimated 12 million children (17 percent) in the U.S. suffer from one or more learning, developmental, or behavioral disability and that number appears to be increasing.

- Mental retardation now affects 2 percent or approximately 1.4 million children under the age of 18.

More Research Needed

Given that these increases are relatively recent and more chemicals that can impact brain development are being manufactured and put in the marketplace each year, environmental exposures are likely a significant reason we are seeing the numbers of neurological problems we are today. That is why we need to increase research in this area. We also need to learn more about how neurotoxicants may contribute to mental retardation relative to various learning disabilities or autism.

Financial Impacts

In the meanwhile, the apparent increases in the incidence of learning and developmental disabilities are already being played out in real world terms. Any kind of neurological disability can have serious adverse consequences for affected children and adults, their families and communities. These can include psychological and economic costs associated with unemployment, school dropout, teen parenting, substance abuse, welfare dependency, and involvement with juvenile and adult criminal justice systems. This means major economic costs for the families and for society at large.

Providing special education to students with disabilities amounted to $77.3 billion in the 1999-2000 school year.

For example, providing special education services to students with disabilities amounted to $77.3 billion, or an average of $12,474 per student in 1999–2000, which is almost 22 percent of the 1999–2000 total spending on all elementary and secondary educational services in the U.S. The total expenditure per regular education student is only $6,556. Economic costs to society for neurodevelopmental deficits amount to $81.5 billion to $167 billion per year

Crime

In addition, researchers and advocates point to studies that find higher percentages of children with disabilities end up in the juvenile justice system. In a report, "Addressing the Needs of Youth with Disabilities in the Juvenile Justice System: The Status of Evidence-Based Research," released by the Washington, D.C. based Urban Institute in May 2003, the co-authors found that children and youth with disabilities have become increasingly overrepresented in the juvenile justice system. Earlier in the year, Dr. Herbert Needleman (who did groundbreaking studies on the effects of lead exposure on children that were instrumental in establishing nationwide government bans on lead from paint and gasoline) released a study in the January 2003 issue of the Journal of Neurotoxicology and Terotology. His research revealed that children who were exposed to lead, a known neurotoxicant, had a higher likelihood of developing delinquent behavior and going into the juvenile justice system. If exposures to neurotoxicants can result in disabilities that, in turn, lead to delinquency, then eliminating these environmental exposures has the potential of not only decreasing the numbers of those with disabilities, but the burden on the juvenile justice system.

Studies have also indicated that in school classrooms poor indoor air quality makes it far harder for children to learn because the toxics in the air can make it more difficult to think clearly and concentrate. Common sense suggests that if a student already has a developmental disability, these unhealthy exposures are only going to exacerbate his or her challenges learning in school.

Why We Should Care

In short, we should care about potential environmental contributors to developmental disabilities for two main reasons: 1) because research is increasingly indicating that known and suspected neurotoxicants may influence brain development in ways

that can lead to disabilities; and 2) because preventing the causes of neurologically-based disability needs to be a priority if we are to have a healthy society in general.

How Are These Concerns Currently Being Addressed?

Forty years ago, the renowned scientist Rachel Carson warned about the problematic health effects of toxic chemical exposures in her groundbreaking book, *Silent Spring*. Her views, however, were mostly met with criticism and controversy. Until relatively recently, elected officials, researchers, health care professionals, and even some advocacy groups were slow to make the connection between health and the environment.

However, with the National Academy of Science's publication of *Pesticides in the Diets of Children and Infants* in 1993, along with other emerging research, many sectors of society have become increasingly aware of the relationship between environmental exposures and the significant rise in childhood cancers, weakened immune systems, asthma, learning and developmental disabilities, birth defects, behavioral disorders, and other health concerns. In fact, a number of organizations and institutions in the governmental, academic, and nonprofit sectors are now focusing solely on these concerns.

Some are working on legislation and regulatory policies that take into account children's unique vulnerabilities. Others are undertaking scientific research to deepen our understanding of what health impacts different chemicals may have. Still others are working on consumer issues or a range of grassroots initiatives, such as eliminating dioxin and mercury in our medical waste stream and mitigating disproportionate pollution exposures in low income and minority neighborhoods. Some are working with industry to ensure greater corporate accountability for the possible health impacts of their products and support for the production of less-toxic alternatives. Others are helping to educate pediatricians and health care workers, while still others are partnering with parents, teachers, youth, health-affected groups, and religious communities.

Though clearly not all these efforts are directly related to developmental disabilities, the work of this diverse range of dedicated groups and individuals is beginning to form a new movement—an environmental health movement—to protect all of us from environmental contributors to health problems. According

to Michael Lerner, president of Commonweal, a health and environmental research institute, this may be one of the major movements of this century—one that integrates the core concerns of human rights and civil rights groups, environmental justice organizations, the women's rights movement, children's advocacy groups, religious and spiritual communities, the labor movement, social development constituencies, medical and public health constituencies, the mind-body health movements and progressive corporate interests. This burgeoning movement is motivated by the health of current and future generations and the planet.

What Can We Do Right Now?

On personal and institutional levels, we can join this movement to protect ourselves, our families and our communities from toxic exposures. We don't have to wait for more scientific evidence to come in. Instead, we can start now by avoiding products treated with or containing known or suspected toxicants and choosing safer alternatives. We can also voice our concerns to policymakers. Some specific steps we can take include:

- Reducing exposures by washing fresh foods and eliminating excessive animal fats as much as possible from our diets since so many of these chemicals bioaccumulate up the food chain in fat tissue.

- Reducing and eliminating "fast" or processed foods from institutional meal programs (such as school lunches) and using whole foods instead.

- Demanding our "right to know" what chemicals are in our environment and in the products we use, and the risks they may pose to current and future generations—not only in the marketplace but in public institutions, such as schools, day care centers and hospitals

- Educating policymakers at local, state and national levels to ensure that policies, legislation, and regulations are implemented that eliminate toxic exposures everywhere we live, work, study, and play.

In essence, this is about implementing the precautionary principle.

Precautionary Principle

The precautionary principle indicates that when there is plausible scientific evidence of significant harm from a proposed or ongoing activity, precautionary action should be taken to reduce or eliminate harm. These actions can include using the safest alternatives and ensuring that the proponent of an activity, such as a manufacturer of a chemical, bears the burden of assessing its safety and of showing that it is both necessary and the least harmful alternative.

We have a fundamental right to live and to raise children in a world free from chemical trespass—a world that does not threaten our health or future generations simply because we eat, breathe, and drink water in the normal course of our daily lives. And we each have an opportunity and a responsibility to ensure that right is not violated. In this context, by identifying and eliminating toxics that may impair healthy neurological development and function, we are actually working to create a healthier world for all.

5. Research: What We Know; What We Don't Know; What We Need to Know

Paper 3

Windows of Vulnerability: How Toxicants and Timing Effect Brain Development

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The Developing Brain

Brain development begins very early in human gestation and continues well after birth through adolescence. Healthy brain development depends on a tightly orchestrated cascade of sequential and concurrent events. During development, brain cells proliferate, migrate to the appropriate location in the brain architecture, differentiate into the correct cell type, and establish connections (synapses) with nearby and distant cells in complex neuronal circuits. Programmed cell death (apoptosis) is important to normal brain development and occurs in two waves in prenatal and postnatal development.

Healthy brain development depends on a tightly orchestrated cascade of sequential and concurrent events.

Disruption of this sequence at any point during brain development can have a lasting impact on brain function later in life. The nature of the impact will depend in large part on the timing of the disruption. Experimental data show that extremely short term exposures to developmental neurotoxicants can have permanent impacts on later brain function, and that the abnormalities observed after exposure to a single toxic agent may vary with the timing of the exposure. The nature of the neurotoxicant, the extent of exposure, and the timing of exposure are, therefore, each important determinants of outcome.

The nature of the neurotoxicant, the extent of exposure, and the timing of exposure will determine the effects on brain development.

Windows of Vulnerability refers to the windows of time during which the developing brain is particularly sensitive to permanent harm by environmental toxicants.

Brain development is controlled by genetic and environmental factors that interact in complex ways. Environmental factors can significantly impact developing tissues, by altering signaling chemicals that mediate brain development (neurotrophins), or by

modifying gene expression. Environmental factors include nutrition, pharmaceuticals, other chemicals, infectious agents, maternal illnesses, and the psychosocial context.

Mental Retardation and Environmental Toxicants

The role of environmental agents in the etiology of MR/DD is poorly studied and little understood. Substantial literature exists concerning impacts of lead, mercury, polychlorinated biphenyls (PCBs), alcohol, tobacco, and a few pesticides. But there needs to be more systematic evaluation of a whole host of potentially toxic agents to which people are regularly exposed and their impact on neurodevelopmental. Research has demonstrated that the developing brain is vulnerable to toxic exposures at levels that have no discernable impacts in adults.

Environmental toxicants can cause permanent genetic changes and developmental disabilities.

While learning, activity level, and memory lend themselves to animal testing and quantitative assessment, mental retardation, which is a combination of both intellectual functioning and adaptive skills, does not.

Co-morbidities

Epilepsy, autism, cerebral palsy, low-birth weight or small for gestational age, visual or hearing disorders, behavioral problems, psychiatric disorders, and micro- or macrocephaly may be associated with mental retardation. Presumably these disorders are additional manifestations of the clinical condition of which mental retardation is a part, but how they may be related to mental retardation is not always clear.

The Causes of Mental Retardation

It is likely that a large percentage of cases of MR have more than one causal factor. It is important, therefore, to have a dynamic view of the individual in the context of biological, physical environmental, and psychosocial factors. A vulnerable individual may develop intellectual function and adaptive skills better or worse, depending on the nature of the environment in which he/she is situated.

Prenatal, perinatal, and postnatal factors may play a role in the development of mental retardation.

- Prenatal: genetic, teratogenic (infections—e.g rubella, cytomegalovirus; chemical agents—e.g. alcohol), central nervous system birth defects/malformations; hypothyroidism
- Perinatal: Intrauterine events, birth trauma, anoxia (low oxygen), neonatal infections (e.g. meningitis)
- Postnatal: Viral or bacterial infections, trauma, tumors, anoxia

Frequently the cause of MR is unknown, and this is more likely in cases of mild than of severe MR. While a number of genetic abnormalities have been identified (Down syndrome, Fragile X syndrome) there are more cases of unknown cause than of known causes for mild MR. Vaccination programs (e.g., rubella) and routine screening for congenital hypothyroidism and PKU have dramatically reduced the incidence of MR associated with those conditions.

Why Consider Developmental Neurotoxicants a "Cause" of Mental Retardation?

A sizeable literature describing the impacts of alcohol, lead, mercury, and PCBs on the developing brain identifies the potential role of environmental agents in the etiology of neurodevelopmental disorders, including mental retardation. In most cases, fetal exposure to these agents must be relatively large in order to cause mental retardation. Other manifestations of impaired brain development are also common, such as hyperactivity, learning and memory disorders, or behavioral abnormalities.

Alcohol

Studies of people with fetal alcohol syndrome show that the IQ distribution curve is shifted significantly to the left (indicating lowered IQ) and includes individuals with severe to moderate mental retardation. Risks of fetal alcohol syndrome depend on the size, pattern, and timing of fetal exposures. Genetically determined variations in maternal metabolism of alcohol also influence the likelihood of fetal alcohol syndrome since one of the metabolites of alcohol, acetaldehyde, is thought to be an important contributor to the condition. Maternal nutritional status and other substance abuse are important additional factors to consider.

Toluene

Maternal exposure to toluene, another organic solvent, is also associated with pregnancy outcomes that resemble fetal alcohol syndrome, and the term "fetal solvent syndrome" (FSS) is now

sometimes used. Glue or gasoline sniffing during pregnancy can result in significant fetal toluene exposures with defects similar to those seen with alcohol, including mental retardation.

PCBs

In the late 1960s and early 1970s two episodes of accidental human exposure to PCB- and furan-contaminated rice oil in Japan and Taiwan resulted in tragic developmental effects in children born to exposed mothers. The developing fetus was much more sensitive than the mothers and numerous abnormalities were observed including low birth weight, hyperpigmentation, swollen gums and eyelids, and mental retardation among some of the most highly exposed. Subsequent studies show that hyperactivity, learning and behavioral problems, as well as IQ deficits, are seen in children exposed to PCBs during fetal development.

Metals: Mercury and Lead

Mercury and lead are two heavy metals that can also disrupt normal brain development via a variety of mechanisms. Large exposures to mercury may cause mental retardation. Early life exposures to lead can also reduce IQ and cause learning and behavior problems. The total incremental impact of lead exposure in a disadvantaged community, however, may be substantially greater than the same exposure in an advantaged community. IQ distributions may differ by as much as 15 points in the two groups because of psychosocial or other factors.

The impact of lead exposure in a disadvantaged community may result in a 15 point lower IQ distribution than the same exposure in an advantaged community.

Additional Answers Needed

Unfortunately, *most industrial chemicals to which people are regularly exposed from consumer products or as environmental contaminants have not undergone neurodevelopmental testing*. A large database addresses the impacts of lead, mercury, PCBs, alcohol, and smoking. For most chemicals, however, very little information is available.

Recent studies show that even mild untreated maternal hypothyroidism can have neurodevelopmental consequences, including lower IQ, in children. Some PCB research has focused on disruption of normal thyroid hormone levels and interference with normal thyroid hormone function during development. This line of investigation has raised new concerns about other

Most chemicals we use every day have never been tested to make sure they are safe for us to use.

chemical compounds that may disrupt normal brain development through similar mechanisms.

PBDEs

Some brominated flame retardants (PBDEs) that are used in large amounts in consumer products have properties that are similar to PCBs. Though they have not been as well studied, animal testing shows that PBDEs can interfere with normal brain development leading to hyperactivity and deficits in memory and learning in adults. Studies show that PBDE levels in human fatty tissue have been rapidly rising in recent years. Some European countries have taken initial steps to limit PBDE exposures, based on biomonitoring trends. In the U.S. no such action has yet taken place, though legislation that would place restrictions on some PBDEs has been introduced in California.

Issues for Discussion

Neurotoxicants

Although the data suggest that fairly large exposures to neurotoxicants are necessary in order to serve as a *primary* cause of mental retardation, the extent to which smaller exposures compromise individuals' intellectual function and adaptive skills is unknown. The impacts of neurodevelopmental toxicants must be considered in the total psychosocial context of individuals and communities.

Neurotoxicants and Prenatal and Postnatal Nutrition

What is the importance of maternal nutritional factors in fetal brain development, and what are the potential interactions of neurodevelopmental toxicants with nutritional deficiencies during critical windows of development?

Do the relative importance of prenatal and postnatal nutritional factors and interactions with neurotoxicants differ?

Paper #4

Methylmercury: A Story of Loaves and Fishes

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What Is Mercury?

Mercury is naturally present in the environment. It may be found in air, water, soil, aquatic sediments, and in living plants and animals. It occurs in several chemical forms, including inorganic and organic mercury compounds.

Mercury is highly neurotoxic, especially to developing fetuses.

Methylmercury (MeHg) is highly neurotoxic especially at high exposure levels. The fetus is especially vulnerable to its neurotoxic effects at doses too low to show postnatal effects.

Human Environmental Exposure to Methylmercury

Around 70 percent of the mercury in the environment comes from anthropogenic sources—primarily emissions from coal-fired electric power generation facilities and waste dumps, although volcanoes and mines are also a source. Increases in power plant emissions and industrial uses over the past 100 years have been accompanied by a three-fold increase in environmentally available mercury. In these forms, mercury remains in the environment indefinitely.

Increases in power plant emissions and industrial uses over the past 100 years have been accompanied by a three-fold increase in environmentally available mercury.

The principal source of human exposure to MeHg is fish consumption. Sea mammals and shellfish also carry variable concentrations of MeHg in their tissues. The predominant source of MeHg in the aquatic environment is atmospheric mercury deposited on the surfaces of bodies of water that is then biomethylated by microorganisms and subsequently biomagnified as it ascends the food chain. Most fish living in U.S. waters have less than 0.5 parts per million (ppm) but some older, larger carnivorous fish at the top of the food chain can contain more than 1 ppm. Tuna, shark, and swordfish all typically exceed 1 ppm.

Most people are exposed to mercury by eating fish.

Although the dominant health concerns arise from gestational exposure, infants and children may be exposed postnatally to MeHg from breast milk should their mothers consume foods containing high levels, or if they consume fish or foodstuffs containing fish products.

Developmental Neurotoxicity of Methylmercury

Fishes

During the 1950s, outbreaks of MeHg poisoning occurred in several places in Japan. The best know of these took place in Minamata and Niigata. More than 21,000 individuals filed claims with the Japanese government as victims of what became known as Minamata disease; almost 3,000 were certified by the government as actually having the disease In Minamata alone, nearly 600 people died. These outbreaks were caused by industrial discharges of mercury into coastal waters or rivers. Fish contaminated by these discharges were subsequently caught and consumed by local residents. Poisoned individuals suffered severe neurological impairments.

More than 21,000 individuals filed claims; almost 3,000 were certified as having Minamata disease; nearly 600 people died.

Loaves

A later outbreak in Iraq resulted from the consumption of bread made from seed grain coated with a MeHg fungicide. This outbreak affected 6,530 individuals, 439 of whom died. The levels of MeHg documented in the fish in Japan and in the seed grain in Iraq were far higher than those occurring from natural dietary exposure.

Congenital Minamata Disease

In Minamata, Japan, pregnant women who consumed the contaminated fish manifested mild or no symptoms, but gave birth to babies with severe developmental disabilities, including cerebral palsy, mental retardation, and seizures. This outcome, called Congenital Minamata Disease, first indicated that the fetal brain may be highly sensitive to MeHg exposure. Following the outbreaks in Minamata and Niigata, 22 cases of Congenital Minamata disease were documented. Their level of prenatal exposure to MeHg was never ascertained and no information is available on dose-response relationships in these children.

Pregnant women who consumed contaminated fish but had no symptoms, gave birth to babies with severe developmental disabilities.

More Loaves

Investigators found that the offspring of 83 women who were pregnant during the Iraqi outbreak had prenatal exposure levels between 1 and 600. In contrast, MeHg levels seen in fish eaters consuming multiple fish meals per week rarely exceed 36 ppm in hair. The results suggested a dose-response curve associated with delayed milestones that appeared to indicate an adverse effect at exposures as low as 10 to 20 ppm in maternal hair. For many years thereafter, these findings were used as a basis for determining the permissible daily intake for methyl mercury exposure. However, the study was not well controlled. Also, the source of exposure in Iraq was not fish consumption and the number of children with neurological findings was small, limiting the generalizability of the results.

More Fishes (and Whales)

In the mid-1980s, two different groups of investigators conducted two large well-designed and well-executed cohort studies—one in the Republic of Seychelles and the other in the Faeroe Islands—that reached different conclusions about the amount of "safe" mercury levels. Upon further examination of their results, the NRC and the EPA recommended lowering the RfD from 0.5 to 0.1 μg/kg/day. The data from the Seychelles study were discounted because no significant adverse effects were reported. Later, the Faeroes group reported that the polychlorinated biphenyls (PCBs) present in whale meat and blubber might be confounding the mercury exposure raising questions about the NRC's conclusions.

Public Policy Issues

There is no doubt that organic mercury is a potent neurotoxicant. Faced with data that point to the increased bioavailability of mercury in the environment, scientists need to inform governments worldwide of the level of exposure that can cause adverse health effects, and governments need to develop public health policies that minimize human exposure. Some governments have promulgated policies and laws that severely limit or eliminate the use of mercury preservatives in vaccines, and inorganic mercury in dental amalgams. Other governments, including the United States have sought to develop public health strategies that limit human consumption of fish during pregnancy.

Unfortunately, the gap between science and policy concerning low-dosage exposure to mercury may not be narrowed for some time. Regulatory bodies in the U.S. such as the Environmental

Regulating the sale of fish high in MeHg may be appropriate.

Protection Agency (EPA) and the Food and Drug Administration (FDA), and bodies such as the Agency for Toxic Substances Disease Registry (ATSDR) have adopted differing views about appropriate actions to be taken. Regulating the sale of fish high in MeHg or advising pregnant women to refrain from consuming fish high in mercury during their pregnancies may be appropriate provided the agencies can agree on what constitutes a nominally safe dose.

In warning the public about the risks of mercury exposure from consuming fish, we face the alternative risk of frightening consumers into refraining from fish consumption when fish is a primary source of nutrition among many groups. Similarly, parents in some parts of the United Kingdom have decided to forego having their children immunized fearing exposure to mercury from the vaccines. Such practices, if they occurred on a large enough scale, could compromise disease control, leading to a greater risk to child health than mercury might present.

Paper 5

Challenges in Studying the Environmental Factors in Developmental Disabilities

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What Does CDC's National Center on Birth Defects and Developmental Disabilities Do?

The Center for Disease Control and Prevention's (CDC) mission is to promote health and quality of life by preventing and controlling disease, injury, and disability. The CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is specifically charged with the prevention of developmental disabilities (DD) and promotion of health in people with DDs. Activities related to this mission include 1) developing scientifically sound prevention programs for the DDs we know how to prevent, 2) conducting research to identify the causes of DDs, and 3) identifying ways to promote the health and prevent secondary conditions in those with DDs. Examples of these activities included monitoring the effectiveness of state newborn blood spot screening programs for metabolic and genetic disorders (many of which result in mental retardation if left untreated), and developing prevention programs targeting women at high risk for an alcohol-affected pregnancy and the resulting fetal alcohol syndrome (FAS) phenotype.

The Center also has an active research program that monitors the prevalence of mental retardation and other developmental disabilities (cerebral palsy, autism, vision and hearing impairment) and has an epidemiologic "centers of excellence program" for research on the risk factors and causes of autism; several of the centers have also recently incorporated mental retardation.

Issues and Challenges in the Epidemiologic Research of Developmental Disabilities

Determining Causes of Mental Retardation

One of the primary challenges in DD research is defining the disease outcome. Most DDs are defined on the basis of the child or individual's functioning. There are no biologic markers of the disorder—most are based on outward signs of functional disability.

There are no biologic markers for mental retardation. Diagnosis is based on outward signs of functional disability.

For example, mental retardation is defined on the basis of IQ (and the child's functioning) with mental retardation at the lower tail of the IQ distribution. It is unclear from an etiologic perspective whether a specific agent, for example lead, impacts the entire IQ distribution or whether there are certain subgroups that may be more adversely impacted due to other environmental or genetic factors. Other agents may only impact the lower tail of the IQ distribution—for example a specific neurotoxic agent that also results in cognitive disability.

Another example is autism that is defined as the presence of three key behavior traits. Again, as with mental retardation it is not clear if autism is an all-or-nothing condition—i.e., either you have it or you don't. Can you be a little autistic? We have created diagnostic categories for individuals who have some, but not all, of the features of autism, but again how a particular agent relates to these various phenotypes is uncertain.

Disabilities Identified Later in Childhood

Another challenge to research is that the features of the disorder don't become immediately apparent until the children are older. Again, using our two examples—autism and mental retardation—the average age at diagnosis for autism is age 4-5 years and for mental retardation, particularly for mild mental retardation the age is considerably later, 8-9 years. This delayed age at identification is particularly challenging when trying to do research because there is a long lag time between initial exposure—usually prenatal or early childhood—and the diagnosis of the disease.

In surveillance or disease tracking, which lays the groundwork or foundation for much research, one of the key objectives of this activity is to serve as an early warning signal for potential epidemic exposures. For developmental disabilities surveillance, the long lag between the exposure and the diagnosis or recognition of the disease, make for delayed identification of an "epidemic exposure" and possibly a missed opportunity to identify an exposure due to dilution by factors effected by time as mentioned above.

Multiple Diagnoses

One final methodologic issue worthy of discussion in the study of DDs is the inter-relatedness between the many DDs. Children with a DD are much more likely to have another DD compared to children without DDs. This is particularly true for certain DDs,

The etiology of children with multiple DDs may, in fact, be different than that for children with only one disability.

such as cerebral palsy and severe MR. We have some evidence to suggest that the etiology of children with multiple DDs is perhaps different than that for children with only one disability. Research into the epidemiology of DD has approached each disorder separately—an integrated approach would, perhaps, offer more insight into the underlying causes of these co-occurring DDs.

What Do We Know about Environmental Factors and Developmental Disabilities?

Maternal Behaviors in Pregnancy

Smoking

Maternal smoking has been linked to mental retardation in a few epidemiologic case-control studies. The magnitude of the increase was 1.6 fold for any smoking with a dose response effect found (increasing to 1.9 fold for one pack per day or more). Other investigators have examined the impact of maternal smoking on various aspects of cognitive functioning and learning—with mixed results.

Alcohol

It is well know that maternal alcohol use (in high levels) results in fetal alcohol syndrome (FAS)—one of the core features of FAS is neurodevelopmental impairment (manifested as mental retardation in some children.) In children who are still impacted by alcohol but not as severely to have FAS, other neurologic and developmental effects are noted, clinically recognized as fetal alcohol effects or alcohol-related neurodevelopmental disorder. In four recent case series, the proportion of FAS cases with measured IQs of 70 varied from 23 percent to 58 percent and the magnitude of the cognitive deficit appears to be in direct proportion to the extent of the physical features of FAS. FAS results from heavy and prolonged exposure to alcohol in utero. However, lower levels of exposure are harmful—an average of two or more drinks per day has been associated with a seven IQ point decline in children.

Toxic Environmental Exposures

It is known that several environmental contaminants (i.e., lead, methyl mercury, polychlorinated biphenols) in high doses can produce serious neurologic damage, including CP and MR. The most famous of these were in Minimata Bay, Japan. The evidence

for lead is perhaps the most clear. Prospective cohort studies of lead exposures have found that among school-age children, a decrease of 2-6 points in mean IQ was associated with previous exposure levels of >20 or >30 μg/dl.

Implicit in these findings is that a shift in the IQ distribution due to lead or other toxic environmental exposures would results in a great proportion of children in the population with mental retardation. Alternative explanations for these findings include the inadequate control of socioeconomic correlates of lead exposure and the possibility that children with initially low IQs are more likely to exhibit behaviors that increase their exposure (i.e., pica).

Of the several studies that have examined the impact of in utero and early postnatal exposure (via breast milk) of PCBs and mercury, principally from fish consumption—the outcomes have been less clear. Two of the three major PCB studies have shown persistent effects on cognitive ability in later childhood. Two of the three long-term studies addressing human exposure to mercury showed long-term developmental outcomes (motor function, information processing, memory, vocabulary, and attention). Importantly, none of these studies showed an increase in the rates of mental retardation or other serious developmental disability, however, it would take a much larger population to examine such effects.

A National Academy of Sciences (NAS) review of the effects of mercury concluded that there was compelling evidence for subtle neurodevelopmental effects from low levels of in utero exposure of methyl mercury. There was not evidence for a threshold for effects—which included women with maternal hair levels of 1-2 ppm. Translating that to the U.S.—about 10 percent of women of reproductive age have hair mercury levels above 1ppm. In addition, populations who eat larger quantities of fish are clearly in the range that is associated with adverse neurodevelopmental problems.

About 10 percent of women of reproductive age have hair mercury levels above 1ppm.

Conclusions and Recommendations

The impact of the environment on DDs is a challenging research area. The long lag time between exposure (in pregnancy or early childhood) and the development of the DD presents some formidable study design issues. Encouraging prospective population-based studies of uniquely exposed populations will

enhance our understanding of the impact of ubiquitous exposures on neurdevelopmental functioning. However, the prospective, targeted studies tend to be small in sample size, limiting the ability to understand how a particular exposure may impact DDs per se. Some of this can be inferred from what we know about "poisoning" episodes—but not all those exist for all outcomes. We can also infer a continuum of response based on our animal models.

Many environmental neurotoxicants need to be further studied, particularly pesticides and phthalates

Also, many other environmental neurotoxicants have not been adequately studied. Top candidates are chemicals that reproductive age women or young children maybe more commonly exposed to, such as pesticides and phthalates.

6. Implications for Our Communities and Our Lives

Paper 6

ARSENIC AND OLD LEAD

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Background

We live in a world that is infused with chemicals and toxicants. Many of these elements make our lives easier and more comfortable. Our homes, both inside and out, are built and furnished with materials that are treated or have substances added to them to make them more durable and attractive. Necessities, including our food and clothing, are subjected to chemical exposures—both natural and synthetic. Common appliances, like washing machines and dishwashers, and conveniences, such as dry cleaners, all require the use of harmful substances. As these toxicants accumulate in fat, blood, organs, hair and nails, or are passed through the body in amniotic fluid, breast milk, urine, feces, sweat, and semen, our health and that of generations to come is greatly threatened.

Two National Reports

Two reports recently issued by federal agencies underscore the magnitude of our environmental problems. The Centers for Disease Control and Prevention report, *Second National Report on Human Exposures* documents the extent to which our bodies are subjected to numerous chemicals and heavy metals on a daily basis. While improvement was found in some areas, e.g., decreased levels of exposure to lead and continine, increased levels of exposure were cited for other toxicants, e.g., phtalates found in common household products such as soap, shampoo, and flexible plastics.

The report issued by the Environmental Protection Agency, *America's Children and the Environment*, found that:

- Almost 8 percent, or 5 million, women of child-bearing age have mercury concentrations greater than the maximum

precautionary level. Children born to these women are at increased risk of cognitive and developmental damage. Mercury in fish is the greatest source of exposure, with coal burning serving as the highest source of mercury.

- Children whose parents worked with pesticides and wood preservatives were at a higher risk for having birth defects and for dying young.

- Pesticides, other chemicals, and radiation may contribute to an increased frequency of some childhood cancers. Children born to parents who work with or use certain chemicals are more likely to have cancer in childhood.

- The number of children having respiratory illnesses, particularly asthma, is increasing due to exposure to air pollution. This has resulted in difficulties in breathing resulting in increased use of medication, visits to doctors' offices, and outpatient emergency rooms and hospitalization.

- Children of women who were exposed to chlorinated solvents have an increased risk for heart and oral cleft defects.

Purpose

The purpose of this paper is to review the common chemicals and metals to which we are exposed daily, and to raise issues about the effects these exposures may have on people with mental retardation and other developmental disabilities. There is little research available regarding the effects on persons currently living with mental retardation.

What effect do environmental toxicants have on people who are mentally retarded?

Implications

Our Homes

The Continuing Lead Threat

Historically, the most well known toxicant found in our homes is lead. Despite decades of evidence that lead is harmful to the developing neurological systems of young children, manufacturers

continued to add this heavy metal to house paint until it was banned in 1978. (It is important to note that this legislation applied only to house paint. Lead continues to be added to other types of paint, e.g., paints used for boats and some art supplies.) The good news is that, as new housing has been built and lead has been removed from paint, gasoline, water pipes, and solder, fewer children are experiencing high blood lead levels. A significant decline in both the number of children with elevated blood lead levels and in the blood level considered to need medical intervention has occurred over the past three decades.

In 1970, the U.S. Public Health Service established a blood lead level of 60 μg/dl as the standard requiring medical intervention. This standard was revised over the years to our current limit of 20 μg/dl for medical intervention and greater than 10 μg/dl for environmental and nutritional intervention in 1991. As a result of changes in the rates of exposure, by 1999–2000 the percentage of this children ages 1–5 with elevated blood lead levels had decreased from 4.4 in the early 1990s to 2.2 percent.

An estimated 38 million housing units throughout the United States contain lead-based paint. This is a substantial decrease from 1990 when an estimated 64 million homes were contaminated. Of those units with hazards, 1.2 million housed low-income families (less than $30,000/year) with children less than 6 years of age. Although 17 percent of government-supported, low-income housing had hazards, 35 percent of all low-income housing had significant lead paint problems. A high proportion of the residents of these housing units are minority populations. The most recent report on Human Exposure to Environmental Chemicals shows that minority children continue to carry a higher lead burden than white children.

Thirty-five percent of all low-income housing had significant lead paint problems, and minority children continue to carry a higher lead burden than white children.

For households with incomes greater than $30,000, 19 percent had hazards. Fourteen percent of all houses had significantly deteriorated lead-based paint, and 16 percent and 7 percent, respectively, had dust lead and soil lead levels above current standards of the U.S. Department of Housing and Urban Development (HUD) and the EPA. Housing in the Northeast and Midwest had about twice the prevalence of hazards as compared with housing in the South and West.

In addition, recent research has demonstrated that even low blood lead levels (below 10 μg/dl) can result in loss of IQ and other

health problems. However, only one third of all children are tested for lead poisoning. The percentage of children with mental retardation who are screened is not known.

Lead has also been found in the paint used on plastics covering our foods, e.g., bread bags, in children's toys, in decaying venetian blinds, in calcium supplements and in many other common products. Lead has been banned from pencils, crayons and chalk. However, many American companies have plants in foreign countries, and despite labeling to the contrary, some have been shown to contain lead upon testing. This is of particular concern for persons with mental retardation who may continue to exhibit pica behaviors beyond the formative years.

Dangerous Toys

In addition to lead, our children are exposed to a multitude of other chemicals and pollutants through their toys. For example, many toys are made from synthetic vinyl that sometimes includes cadmium and other toxicants. Beginning in infancy with coolers that hold breast milk and continuing throughout their formative years, children play with and use hundreds of vinyl-based products on a daily basis. Some common products are teething rings, backpacks, dolls, coaxial cables for computers and computer games, placemats, raincoats and hats, and costume jewelry, to name a few.

Some teething rings, backpacks, dolls, placemats, and toy jewelry are made from synthetic vinyl that can include cadmium and other toxicants.

Other Dangers

Our homes include other agents that have toxic effects on child development and our health. Children exposed to tobacco smoke have increased bouts of ear infections, upper respiratory infections, and colds. The levels of continine, a metabolite of nicotine, dropped significantly for all age groups from 1991-1994 to 1999-2000. However, in 1999-2000, continine levels in children were more than twice that found in adults. Non-Hispanic blacks had levels more than twice those of Mexican-American and non-Hispanic whites. Tobacco smoke, as well as dust and dust mites, molds, furry pets, and roaches, are all triggers for asthma and allergies.

Combustion products are gases and fine particles produced when any fuel is burned. All of these products are unhealthy, causing irritation and illness. In normal operation of a furnace, these pollutants go up the chimney, but these pollutants are also produced by fuel-fired space heaters and gas ranges. When appliances are not properly vented, combustion products collect in

the building and may include formaldehyde, oxides of nitrogen, carbon monoxide, carbon dioxide, and other chemicals as well as fine particles of soot.

Our Food

Pregnancy and Breast Feeding

Our daily food is not immune from toxicants. While studies have shown that lead stored in bones is released during pregnancy, recent investigations are beginning to document that breastfeeding may also stimulate and promote the release of lead from bone. Children who were exclusively breast fed by their mothers had higher blood lead levels than children whose mothers both breast fed and used formula and those who were not breast fed at all.

Fish

High levels of mercury, commonly found in fish like tuna, have also been found in breast milk. Because this metal remains in the body, and travels easily through the placenta and into breast milk, women of childbearing age need to limit some fish intake before and during pregnancy and while breastfeeding.

Despite research on the benefits of eating fish, this food source has emerged as a host for a broad assortment of pollutants. Mercury, polychlorinated biphenyls (PCBs), dioxins, flame retardants, and other toxic chemicals build up in fish and seafood. Big predatory fish tend to have higher pollutant levels. Fatty fish species tend to carry higher levels of PCBs and dioxins. Mercury and PCBs are particularly toxic to the brain, so exposure early in life when the brain is still developing can lead to IQ loss and changes in learning and behavior.

Mercury, PCBs, and dioxins have been found in fatty fish like salmon and tuna.

Vegetables, Grains, and Meat

Lead arsenate was used as a common pesticide for decades and leached into our foods (carrots, onions, potatoes, and other root crops as well as fruits and grains). Currently, there are no federal regulations requiring fertilizer manufacturers to test their products to determine the amounts of heavy metals, dioxin, or other pollutants they may contain, nor are fertilizer companies required to list the sources from which they obtain minerals.

Cadmium, chromium, dioxins, and mercury are also found in many vegetables. These metals have been found to have known or probable carcinogenic effects. Some (dioxins, lead, and mercury)

have been linked to infertility, birth defects, and neurological system abnormalities. Some heavy metals do occur naturally in the environment, e.g., rock phosphate fertilizers contain high levels of cadmium. However, many micronutrient fertilizers contain heavy metals and dioxins that come from the "recycling" of hazardous industrial waste. These include aluminum or copper smelting, the manufacture of cement, and steel production.

Humans are subjected to numerous chemicals and pollutants through meats and poultry. Both types of livestock are subjected to high levels of toxicants through their feed both that occur naturally or through additives as well as through the air.

Our Day Care Centers, School, Work, and Leisure

It is impossible to name an environment where we spend our time in which we are not subjected to pollutants. Paints, varnishes, solvents, pesticides, new carpets, and poor indoor air quality and inadequate ventilation in schools can be harmful to children's physical and mental health. From aggravating asthma and allergies to causing cancer and brain damage, these powerful toxicants may be at the root of illness and behavior problems for millions of children. Most states, for example, do not have regulations regarding where child day care centers can be situated. Thus, many are based in church basements, old buildings and other places that are covered with lead-based paint.

Recess and outdoor athletic events do not necessarily provide our children with a breath of fresh air. A recent report by the National Environmental Trust (NET), Physicians for Social Responsibility (PSR) and the Learning Disabilities Association of America (LDAA) estimate that industry releases 24 billion pounds of neurological toxicants annually. However, only 5 percent of the estimated total emissions, 1.2 billion pounds, are reported to the EPA.

With over 80,000 chemicals included in the federal inventory, it is impossible to calculate the number of neurological toxicants to which Americans are exposed in their workplaces—and which may be carried home in their bodies and in their hair and nails or on their clothes. For example, the safety and health topics page for the National Institute for Occupational Safety and Health (NIOSH) includes about 70 different topics, each of which has numerous subcategories. One of these topics is relevant to environmental workplaces and persons with mental retardation and is one of the very few instances of documented concern in this area.

Sheltered Workshops

In 1998, a representative of NIOSH contacted The Arc of the United States and met with its Health Promotion and Disabilities Committee to discuss environmental health and work safety practices for persons with mental retardation working in sheltered workshops. As a result, NIOSH conducted a health hazard evaluation of one workshop and found that sheltered workshop employees had low management awareness of worker health and safety issues. Because of these findings and an inability to identify additional occupational health and safety information, NIOSH evaluated 10 additional sites. In 1999, NIOSH published a report, "Protecting Workers with Developmental Disabilities" in the February 2000 issue of *Applied Occupational and Environmental Hygiene.* and has made the report available on its website. Exposure of chemical and physical agents, hazard communication training, pica behaviors, and warning devices and alarms are among the topics addressed.

See the NIOSH website for "Protecting Workers with Developmental Disabilities" in *Applied Occupational and Environmental Hygiene*. The report addresses exposure of chemical agents, pica behaviors, and warning devices.

The specific types of work that persons in sheltered workshops carry out are of concern as well. Some instances of poor environmental conditions have been reported to The Arc of the United States. While two examples are offered that are anecdotal, it is likely that such situations are common. First, plastic shrink wrapping of packages was the primary occupation of one workshop. The site did not have proper ventilation, resulting in employees being subjected to toxic fumes and high heat levels. In addition, safety precautions were minimal and burns were common.

In the second instance, manufacture of lead fishing weights was the primary occupation. Several employees became ill. However, because these employees had secondary conditions relative to their mental retardation, their behaviors were not immediately associated with their occupational exposure to lead. Ultimately, they were tested and found to have blood lead levels elevated high enough to be in need of medical intervention.

Conclusions and Recommendations

Assumptions

Assumption 1

People whose neurological systems may already be compromised may exhibit behaviors, illnesses, and secondary conditions following exposure to pollutants. It is likely that these conditions

are attributed to the primary cause of the disability rather than resulting from the noxious exposure.

Recommendation

Little or no research into the effects of toxic exposure on people with mental retardation has been conducted. The effects of different toxic thresholds on differing etiologies have not been determined. And the contribution of toxic exposures to poorer intellectual, physical, behavioral, and mental health is not part of any research agenda.

It is, therefore, recommended that developmental disabilities and environmental health (EH) organizations join forces to work with federal agencies, e.g., NICHD, CDC, the Office of Disability and Health, to develop and implement a research agenda addressing secondary conditions arising from toxic exposures.

DD, EH, and government organizations need to work together to research secondary conditions caused by toxic exposures.

Assumption 2

Toxic exposures affect everyone. Differences in the expression of the outcomes may be attributed to age (e.g., child versus adult), and socioeconomic standing. Socioeconomic status is greatly influenced by race and ethnicity. People with mental retardation are just as likely to be as adversely affected as all other populations.

Recommendation

It is recommended that developmental disabilities and environmental organizations work with CDC, the National Center for Health Statistics (NCHS), and other federal agencies to identify and include the DD population in their surveillance systems. (No system currently exists to determine the prevalence of developmental disabilities. It is also recommended that CDC, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) implement a national surveillance system specific to developmental disabilities.)

Assumption 3

For the most part, our health care providers do not know more about environmental exposures than most patients. One-quarter of medical schools offer no instruction in environmental medicine, and those that do offer less than 10 hours over four years.

One-quarter of medical schools offer no instruction in environmental medicine.

Recommendation

The lack of education and training in environmental health among our health care providers must be rectified. Recently, the NCBDDD funded four regional Fetal Alcohol Syndrome Training Centers. The purpose of these centers is to develop and implement a standardized curriculum to be used by medical schools and other allied health professionals and as part of continuing education programs. DD and EH partners should work with CDC and other relevant agencies to develop and implement a similar program for training medical and allied health personnel in environmental health. The curriculum should include training in the possible effects of toxic exposures on persons with developmental disabilities.

Assumption 4

We really know very little about the effects of most modern day pollutants. Under the Toxic Substances Control Act (TSCA), chemical companies are allowed to release new compounds on the market without required comprehensive safety testing. Some conduct rudimentary research, but fewer than half include any toxicity data. Eighty percent of new chemicals receive approval in less than three weeks, with an average rate of seven a day.

Recommendation

DD and EH collaborators should work with Congress to enact legislation that safeguards U.S. citizens by mandating testing of all possible toxicants before they are allowed on the market. In addition, Congress should re-enact and tighten legislation to control industrial and automotive emissions, toxic dumping, and enact and enforce other related health and environmental standards.

Finally, the President extended the Executive Order for the Task Force on Environmental Health and Safety Risks to Children in April 2003. Co-chaired by the EPA and the U.S. Department of Health and Human Services, the Task Force has undertaken the National Children's Study which will follow about 100,000 children before birth, through childhood, up to adulthood to investigate the relationships between environmental exposures and potential health effects. DD and EH partners should ensure that the study's sample includes children born with mental retardation and other developmental disabilities.

Paper 7

FACILITIES FOR SPECIAL EDUCATION: LEARNING THE HARDER WAY

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How Safe Are Our Schools?

More than a third of America's public schools need major repairs or total replacement according to a state-by-state study published in 2000 by the National Education Association (NEA). In addition, 26 percent of schools reported ventilation as unsatisfactory, 20 percent reported poor heating, indoor air quality, acoustics, noise control, and physical security, and 12 percent reported unsatisfactory lighting conditions in another nationwide survey. A 1995 U.S. GAO study benchmarked conditions in all the states. EPA considers indoor air pollution a top human health hazard since indoor air is 5 to 100 more polluted than outdoor air.

Schools are our children's workplaces. Generally, at least four times more densely occupied than adult commercial office spaces, these workplaces have a profound and far-reaching impact. There are over 50 million children currently enrolled in our schools, spending as many as 40 or more hours each week in school facilities, and an estimated 30 percent of all school children—17 million in all, or more than the population of all but a few states—are in schools that daily erode health and learning. Asthma accounts for an estimated 10 million missed school days. One-third of Washington, DC teachers surveyed recently reported missing school due to facility impacts on their health. Asthma is a common occupational hazard for school personnel.

Thirty percent of all school children—17 million in all—more than the populations of most states—are in schools that daily erode their health and learning.

Children suffer from a wide range of health and behavioral effects linked to these poor school environments, and specifically to environmental pollutants—including asthma, nausea, dizziness, vision and perceptual problems, learning disabilities, irritability, developmental delays, and such long-term illnesses as leukemia and cancer.

Asthma, dizziness, learning disabilities, vision problems, developmental delays, and cancer have been linked to poor school environments.

These conditions also affect the wellbeing of teachers and other school personnel. Unlike children, however, school personnel can

turn to their unions, invoke Occupational Safety and Health Administration (OSHA) in 26 states, and everywhere look to bargaining contracts on their behalf. The National Institutes of Occupational Safety and Health (NIOSH) can study the health and exposures of the five million adults who work in schools, but no comparable system of research, standards, or protection exists for students. And no state has a student illness or injury reporting system; there is no baseline data on the health of any set of students.

Children Are Especially Vulnerable

The lack of protection for children is even more worrisome in light of their special vulnerability to environmental health hazards. Children are particularly at risk because: 1) their bodies are still developing; 2) they proportionately eat, drink, and breathe more per pound of body weight than adults; 3) they are exposed to more environmental threats; and 4) they are less able to protect themselves from hazards.

What Are the Vulnerabilities of School Age Children?

AGE	DEVELOPING SYSTEMS	WHAT TO LOOK FOR
Young child (2-6 yrs)	Brain, lungs, small intestines, immature detox capacity	Pesticides, floor level air pollutants, lead, mercury, allergens
School age (6-12 yrs)	Brain, lungs	Air pollutants, arts & crafts, pesticides
Adolescent	Brain, lungs, rapid growth sexual maturation	Occupational hazards, drug abuse, air pollutants, arts & crafts, trade school hazards, pesticides

Adapted from Agency for Toxic Substances and Disease Registry (ATSDR)

Are Children with Special Needs at Greater Risk?

For a more detailed discussion of school environmental hazards, read "Learning the Harder Way," *Environmental Health Perspectives*, June 2002.

Facilities for Special Education: Learning the Harder Way raises questions about what we think we know and the new systems that need to be in place to ensure that every child has an environmentally safe and healthy "workplace"—a school that is clean and in good repair. Do students in special education have the "buffering capacity" to offset

the effects of a poor school environment? Do they have disproportional exposures to toxics in school? That is, are environmental conditions and toxics making education even harder? A few cases will illustrate the complex issues of students and school environmental exposures:

> A distraught father of a student with multiple disabilities in a 12-month program called HSN to learn why his son's health was failing. The father visited the summer school site only to see barrels of construction chemicals filling the halls along with demolition dust and fumes hanging in the air. The school was under total renovation. All students and staff were daily exposed to multiple pollutants.
>
> Miriam, the grandmother of a wheelchair-bound student in special education at one of New York City's Schools of Ground Zero, helped evacuate students on September 11, 2001. Because of the fumes and particulates in the air, school personnel and many students who returned to the facility became ill. While personnel took their cause to city and federal agencies, no agency protected students. Indeed, Miriam chose not to advocate: she feared losing her grandson's placement and losing her own job at the same school which allowed her to provide the daily personal care the city schools could not guarantee.

National Efforts to Improve School Safety

Recognizing the crisis at hand, Congress passed the federal "healthy and high performance schools" (HHPS) provisions of Leave No Child Behind Act of 2001. HHPS requires the U.S. Department of Education to conduct a study on the impacts of decayed schools on child health and learning.

Founded in 1995, HSN's mission is to assure every child and school employee an environmentally safe and healthy learning environment through research and data analysis, information and referral, advocacy, and coalition building. HSN coordinates the national ad hoc Coalition for Healthier Schools, and runs the Healthy Schools/ Healthy Kids Clearinghouse.

The EPA school environments work group found that school administrators and officials have no training or background in environmental health issues, and since there is no public system to track these issues, identifying problems where they exist and targeting them for remedial action is impeded.

Stressing the need for child health protection at school, the U.S. Senate Committee on Environment and Public Works held a hearing on school environments on October 1, 2002, chaired by Vermont's Senator Jim Jeffords who has since issued a report to Congress urging action on HHPS, setting standards for school air quality, and other measures.

F. Policy Realities: Why We Are Not Protected

Paper 8

The Emperor's Clothes: Why Aren't Chemicals Tested for Their Impacts on the Developing Brain…Why Is This Important?

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Surrounded by Chemicals

More than 80,000 commercial chemicals are now registered with the Environmental Protection Agency and another 2,000-3,000 new chemicals are registered each year. These agents are used in industrial processes, put into consumer products, and intentionally added to the food chain. The U.S. Congress' Office of Technology Assessment (OTA) has estimated between 3 and 5 percent of non-pesticide chemicals—or 2,400-4,000 in total—to be nervous system toxicants. In 1997, known or suspected neurotoxicants comprised nearly three-quarters of the top 20 toxic chemicals released by large U.S. industrial facilities, as reported by the Toxics Release Inventory (TRI)—1.2 billion pounds worth in total. It has been conservatively estimated that 68 million children have had toxic exposures just to lead in gasoline.

The Congressional Office of Technology Assessment estimates that 2,400–4,000 non-pesticide chemicals are nervous system toxicants.

As with the intentional introduction of lead—a known neurotoxicant—to gasoline in the 1920s, the public has often been reassured with claims that widespread commercial use of chemicals will not expose children to risks. In recent years this notion has been repeatedly dispelled as techniques for detecting chemical traces have improved and as the Centers for Disease Control and Prevention (CDC) began its initiative to monitor the blood and urine of adults and children for traces of a wide range of environmental pollutants.

In 1997, known or suspected neurotoxicants—toxicants that affect brain development—comprised nearly three-quarters of the top 20 toxic chemicals released by large U.S. industrial facilities.

We therefore now know that young children routinely carry detectable levels of lead, mercury, PCBs, dioxins, flame retardants, and certain pesticides, among other neurotoxicants. Several known

or suspected neurotoxicants are known to travel across the placenta, while others have been found in meconium (a baby's first stool), both indicating in utero exposure. Breast milk contamination with many such compounds adds to health concerns. In several instances, it also has been discovered, industry has made claims that children's exposure to neurotoxicants was benign or nonexistent while suppressing direct evidence to the contrary. In other cases, industry assurances have been based more on wishful thinking than on the results of good scientific testing.

False Assumptions Underlying Chemical Regulation

Now that scientific evidence makes it impossible to deny that children are routinely exposed to multiple neurotoxicants on a daily basis, the public is receiving reassurances of a different sort. These include the following sorts of claims:

FALSE CLAIM #1: Children's exposure to neurotoxic chemicals are generally of insufficient magnitude to pose risks to children (i.e. the dose makes the poison).

FALSE CLAIM #2 If any of these chemicals constituted a true hazard to children, we (society) would have taken note by now (i.e. injured or dead children could be counted).

FALSE CLAIM #3 Before being put on store shelves or the commercial market, federal laws require that neurotoxic chemicals be extensively tested for safety, including their safety to children and fetuses.

Collectively, these claims are more or less the cornerstone assumptions underlying the entire U.S. system or "regime" for regulating commercial chemicals. Individual chemical risk assessments largely take these assumptions as a given. However, firm science suggests they often are wrong. Each is worthy of longer discussion, but this paper deals solely with the third assumption.

Extensive Testing to Ensure Safety Is NOT Required

Polling suggests that many Americans discount health concerns about exposures to environmental chemicals due to their very strong belief that any product allowed by the government to be marketed must have already been thoroughly tested for safety. One wants to believe it. And the EPA and regulated industries often claim it. But it is simply not the case, and least not from the perspective of parents or children.

Americans believe that the products on their store shelves must be safe or the government would not allow them to be sold.

As described in *In Harm's Way: Toxic Threats to Child Development*, the existing requirements and regime for testing commercial chemicals—especially in terms of their potential for inducing neurotoxicity to the developing fetus or child—is a case of the *emperor having no clothes*. The illusion of comprehensive safety testing probably persists, at least in part, because regulated industries have a strong incentive to perpetuate it, but also because of the technical nature of the issues involved, and not least because the statutory requirements for such testing are quite opaque to public scrutiny.

Testing of Organophosphate Pesticides

Some public health failures of the current U.S. regulatory "regime" for chemical safety or toxicity testing can be illustrated by looking at the body of testing typically performed for pesticides used on food crops, especially those from the organophosphate (OP) class. Codified testing requirements for the more than 520 pesticides approved for use on food crops are much more rigorous than those for other classes of commercial chemicals. If safety testing for these food-use pesticides is inadequate, therefore, one can safely assume the gaps are worse for non-pesticide chemicals. OPs were specifically designed to be toxic to the brain and nervous system; EPA in fact considers the OPs as a class to be the most toxic of all registered pesticides.

The public health failures of the U.S. chemical testing regime fall into several categories, as discussed below:

1. The requirements for basic toxicity testing are outdated.

Under U.S. laws regulators can demand toxicity testing when a particular chemical product is first registered, or is re-registered with the EPA. The toxicity testing requirements for registering pesticides used on food were last revised 20 years ago when much less was known about pesticides and children's vulnerability to them. EPA has repeatedly acknowledged the deficiency of these requirements, particularly for determining the potential impact of pesticide exposure on the nervous system.

Toxicity testing requirements for pesticides used on food were last revised 20 years ago.

EPA proposed revisions to the regulations in 1994, 1998, and 2000, but has failed to ever bring its revisions to the Office of Management of Budget (OMB)—a prerequisite for proposing a rule change. Another problem is that as of the year 2000, the toxicity of many pesticides registered *prior to 1984,* including many Organophosphate (OP) insecticides, still had not been reviewed under the relatively newer, though inadequate, 1984 requirements. This resulted in a situation where some decades-old neurotoxic OPs remained in widespread use on foods or in homes even after EPA acknowledged the manufacturers had failed to submit all of the tests for neurotoxicity required after 1984.

2. The core requirements for food-use pesticides include NO specific testing for potential toxicity to the brain or nervous system.

Deficiencies in the 1984 requirements are many. Among the most basic, however, is that there is *no core requirement that all pesticides used on foods be tested for their possible toxicity to the brain or nervous system.* Several EPA-approved protocols exist for how pesticides might be tested for neurotoxicity, but requirements for doing such tests are "conditional." That is, EPA could "conditionally require" that a given pesticide be tested for its neurotoxicity, but only if other "core" tests had already signified neurotoxicity. Core, required testing for food use pesticides include several kinds of tests, including acute toxicity, chronic toxicity, mutigenicity, reproductive toxicity, and teratogenicity. But, the core tests do not assess neurotoxicity. Thus, "conditional" testing is contingent on a positive neurotoxicity finding from a battery of core tests is not designed to test neurotoxicity.

The EPA does not require that pesticides used on foods be tested for toxicity to the brain or nervous system, even though OP pesticides are specifically designed to be toxic to the brain and nervous system.

EPA, first recognizing the problem in 1994, proposed that revisions include a core requirement to test *all new* food-use pesticides for neurotoxicity. By 1998, in fact, EPA had fashioned an entirely new neurotoxicity screening battery for this purpose. But, again, these EPA revisions never went forward.

3. Individual tests of toxicity are inadequate for assessing potential harm to children and fetuses.

From a child's perspective, it is not sufficient simply to test a chemical for its potential toxicity. The test itself has to be sensitive for evaluating impacts on the developing brain and nervous system. In 1993, the National Research Council (NRC) determined that protocols for EPA's core toxicity tests do not sufficiently address the potential effects of pesticide toxicants on the developing brains and metabolisms of children.

The National Research Council determined that the EPA testing protocols do not sufficiently address the effects of pesticide toxicants on the developing brains and metabolisms of children.

More specifically, all but two of the EPA-required core tests are performed in adult animals. One of these does not assess potential effects on brain or other organ function in infants and toddlers. In other words, impacts on sensitive traits such as behavior, learning, or memory are not tested. Neither of the two studies includes much more than crude measures of chemical insult to the developing brain and nervous system.

Nor are EPA's individual "conditional" tests of neurotoxicity particularly sensitive for endpoints of concern. For example, they lack any quantitative assessment of behavior, or measure of effects on learning and memory. So, these second-tier studies are also insufficient for assessing safety vis-à-vis an exposed child or fetus.

While animal testing generally has been essential for assessing chemical risks, the individual animal tests currently used have limitations. Testing animals for neurodevelopmental endpoints such as learning, attention, and memory, is difficult and inexact. For very few agents do toxicity data from both animal and human studies exist of sufficient quality to allow for direct comparison as to their sensitivity. Looking at such data for methylmercury, PCBs, and lead, however, Deborah Rice concludes that the animal tests typically relied upon by EPA for regulatory purposes were 100 to 10,000-fold less sensitive than the human studies at determining levels of exposure to these neurotoxicants that were "safe."

EPA does recognize that animal and human data aren't equivalent. That's why in its regulatory decisions, it will often use a tenfold "uncertainty factor" to modify its animal data as it extrapolates to a regulatory level for human exposures. Rice's study shows that when regulators only have animal data for known and suspected neurotoxicants, (which is most of the time), its use of this 10X uncertainty factor can result in legal exposure levels that are far too high to protect women and children. This accords with observation that what we formally considered to be "safe" exposure levels for lead, for mercury, for PCBs, now far exceed our notion of what is toxic.

4. Core requirements for food-use pesticides include NO testing for potential effects on the developing brain.

Since 1991, EPA also has had a validated protocol for how to specifically test a chemical for its potential toxicity to the *developing* brain and nervous system. In fact, EPA officials announced in 1998 their intention to propose revisions to the "core" pesticide toxicity testing requirements that would have mandated the developmental neurotoxicity (DNT) testing. In January 1999, the EPA's panel of scientific advisors agreed with this step pointing out that even when DNT testing wasn't quantitatively more sensitive than other required studies, "it provides important qualitative data not obtained in other types of testing."

By May 2000, pesticide manufacturers had submitted DNT studies for just nine pesticides of nearly 900 registered, 140 of which EPA acknowledges to be neurotoxic. EPA scientists in scientific review committees had previously recommended DNT testing for an additional 26 chemicals. Unfortunately, these recommendations impose no obligation on the manufacturers. Additionally, in 1991 EPA obtained the authority from the OMB to "call-in" data from DNT testing for certain chemicals when specific "triggers" or criteria had been met. In September 1999, EPA exercised this authority by beginning a data call-in for manufacturers of the 140 pesticides known to be neurotoxicants. The first phase, which called in DNT studies for more than 30 organophosphate insecticides, required the results of such studies to be submitted to EPA within 2 years. By fall 2001, however, only a third of the studies had even been started with EPA and industry still discussing *how* testing for the majority should be performed.

It is worth noting that EPA's core testing requirements for pesticides also fail to address other important endpoints of concern

to children's health, like the potential for hormone disruption or toxicity to the immune system. Unlike development neurotoxicity, however, EPA has yet to formally validate a protocol for *how to do* this type of testing.

Conclusions and Recommendations

As Dr. Schettler has noted, a large percentage of cases of mental retardation are likely to have more than a single cause; in many individual cases, multiple causative factors probably interact, among them genetics, infectious agents, birth and other trauma, hormonal factors (hypothyroidism) and chemical agents. Many studies demonstrate that fetal exposure to alcohol and other solvents, PCBs, and heavy metals (mercury and lead) can contribute to neurodevelopmental disorders including mental retardation, although the exposures responsible for the latter generally have been large. Lower level exposures to these agents can cause declines in IQ, in the case of lead even at levels below those considered to warrant action under current CDC guidelines. Evidence of this has been gathered for the relatively few neurotoxicants for which large epidemiological studies have been conducted.

In contrast, study of the contribution of environmental chemicals to mental retardation is limited. Regulation for the vast majority of the 80,000 commercial chemicals in commerce depends on testing in laboratory animals. And, as Schettler points out, there is no good animal model for studying mental retardation as an endpoint of concern. Traits of neurodevelopment can be measured with existing animal studies, however, including learning, attention, activity level, and memory. Much evidence exists to link impairments of these traits with relatively lower level exposures to environmental neurotoxicants mentioned above. However, as noted previously in this discussion, the protocols for doing such testing are not required of chemical registrants, nor are they generally performed. The general lack of requirements that chemicals being introduced to the market be systematically evaluated for their neurodevelopmental impact may well contribute to the lack of demand for EPA and other regulatory agencies to assess specific chemicals' toxicity for their potential contribution to mental retardation.

Regulation for most of the 80,000 commercial chemicals depends on testing in laboratory animals, and there is no good animal model for studying mental retardation. But research links impairment of measurable neurodevelopment traits with relatively low level exposures to known environmental neurotoxicants.

The implications for anyone concerned about potential chemical contributors to developmental disabilities, including mental retardation, are fairly profound and lead to the following recommendations:

Recommendation 1

Advocates for preventing neurodevelopmental disorders should become more familiar with the flaws of the current regime for testing chemicals. More specifically, to address the inadequacy of "core" testing of pesticides—at least 140 of which are known neurotoxicants—children's advocates ought to push for the EPA to send its long overdue revisions to the testing requirements (found in Part 158 of the Code of Federal Regulations) to the Office of Management and Budget, and to continue to pressure OMB to approve EPA's issuance of a proposed rule.

Recommendation 2

Being long overdue, organophosphate insecticide manufacturers subject to the 1999 "call-in" of DNT data should face immediate sanctions and/or withdrawal of their products from the market pending the overdue completion of these studies.

Recommendation 3

EPA issuance of the remaining phases of the DNT data call-in, covering the rest of the 140 neurotoxic pesticides known to EPA, should proceed on a strict timeline with similar sanctions facing those failing to comply with deadlines.

Recommendation 4

Given the lack of mandated developmental neurotoxicity testing, the snail's pace of any additional DNT testing under the existing "tiered" testing regime, and the backlog of up to 4,000 neurotoxic chemicals already being legally emitted into the environment without DNT testing, *there can be little expectation of expeditious testing of already-approved chemicals*. Therefore, children's advocates should consider sponsoring amendments to the Toxic Substances Control Act (TSCA) and the Federal Insecticides Fungicides Registration Act (FIFRA) that would institute restrictions on environmental releases of existing chemicals pending the submission of DNT testing that can provide assurance with reasonable certainty that pregnant women and children exposed to such chemicals will suffer no harm. This amendment essentially would shift the onus onto

chemical registrants to prove the safety of their products in exchange for the public license to sell them.

Recommendation 5

Similar amendments to the same laws could require that the 2,000-3,000 new chemicals registered each year must undergo neurodevelopmental testing according to the most up-to-date techniques prior to receiving approval for sale and use.

Recommendation 6

Current CDC programs that monitor levels of chemicals in children and adults, as well as the National Children's Health Study, should include biomonitoring of children for as many of the 140 known neurotoxic pesticides as possible in addition to heavy metals, PCBs and dioxins, and other known neurotoxicants in the environment.

Recommendation 7

Comprehensive surveillance for neurodevelopmental disorders should occur at the national level. Specifically, we recommend that CDC, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) should implement a national surveillance system specific to developmental disabilities including people with mental retardation.

Paper 9

Failure to Protect: Why Current Laws Don't Protect Against Chemical Exposures… Directions for Reform

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Profound environmental health threats to Americans, including the risk of adverse learning and developmental impacts, continue today despite decades of increasing knowledge about these threats. This situation exists primarily because laws and regulations enacted decades ago to protect public health more effectively protect chemical manufacturers, companies that are neither required to assess the health impacts of their products nor obtain government approval for their use. This paper 1) briefly reviews the threats posed by current use of largely unregulated chemicals, 2) examines how current policies protect the chemical industry at the expense of public health, 3) describes recent developments and opportunities related to protecting public health and human development against chemical exposures, and 4) outlines a direction for a collaborative effort to enact protective policies.

The Threat Posed by Toxic Chemicals and How It Was Allowed to Happen

In short, the threat to health and human development has three parts:

1. The chemical industry has made our society dependent on tens of thousands of synthetic chemicals, many of which are known to be toxic to human health, including learning and development, or whose effects on human health and the environment are unknown.

The ubiquitous use of toxic chemicals in our society did not exist three generations ago; global use of chemicals grew from 1 million tons per year in 1930 to 400 million tons per year in 1998.

Global use of chemicals grew from 1 million tons per year in 1930 to 400 million tons per year in 1998.

Chemical companies have informed the government of approximately 80,000 chemicals in use. This glut of chemicals presents two threats to health and development. First, the threat we know about: roughly 1,400 chemicals have

known or probable links to health conditions like cancer, birth defects, or our ability to reproduce. The state of California lists more than 240 chemicals known to cause developmental disorders. Some of these chemicals' developmental impacts have been known for centuries, as is the case with lead and mercury; some chemicals' potential impacts on development are only now being discovered. For example, in recent years researchers have discovered that PBDEs, chemicals used widely as flame retardants, can impair brain development, and Bisphenol-A, a component of many plastics, can cause a chromosome defect associated with Down Syndrome.

1,400 chemicals have known or probable links to cancer, birth defects, or our ability to reproduce.

The threats we know about pale in comparison to what we don't know: approximately 90 percent of the chemicals produced in the highest volumes lack publicly available data necessary for even the most crude toxicity screening. Seventy-seven percent of the chemicals (excluding pesticides—some of which are known neurotoxicants—and pharmaceuticals) registered for use lack publicly available screening-level data on potential developmental impacts. The continuing use of these untested chemicals amounts to an uncontrolled chemistry experiment where humans, and particularly children, are the lab rats.

90 percent of the chemicals produced in the highest volumes lack public data necessary for even the most crude toxicity screening.

2. The chemical industry has created a world of practically universal contamination and exposure to toxic chemicals—through products sold to consumers and through pollution and toxic waste sites generated by factories—resulting in real damage to health and the environment.

Humans are already exposed to these tens of thousands of chemicals in myriad ways every day. Many of these chemicals are placed in products. Furniture cushions, textiles, and electronics products contain PBDEs—which can damage brain development—to reduce flammability, despite the availability of safer alternatives. Baby bottles, food containers, and linings in metal food cans contain Bisphenol-A, associated with chromosome defects, cancer, and endocrine-related health conditions. Many thermometers

Some baby bottles, children's toys, food containers, furniture, and electronics contain chemicals capable of causing chromosomal defects, developmental disabilities, cancer, and reproductive problems.

contain mercury, known to impact learning at very low exposure levels. Children's toys and medical devices contain phthalates (pronounced 'tha-lates') linked with developmental impacts on the reproductive system. These are only a few examples.

Chemicals also end up reaching humans through the natural environment. In 2001, U.S. industries discharged 6.2 billion pounds of toxic chemicals directly into water, land, and air, and generated 26.7 billion pounds of toxic waste. (This only includes the fewer than 700 chemicals for which pollution reporting is required.) This pollution, over time, results in contaminated sites that then present ongoing exposure threats to the public. One in four Americans lives near a Superfund site; studies have shown that children born within a quarter-mile of a Superfund site are at greater risk of birth defects.

In 2001, U.S. industries discharged 6.2 billion pounds of toxic chemicals directly into water, land, and air, and generated 26.7 billion pounds of toxic waste.

These exposures result in damage to health and development. Every year Americans place thousands of calls to state health departments suspecting unusual clusters of disease or other health conditions. These include a cleft lip/cleft palate cluster in Dickinson County, Tennessee, a cluster of neural tube defects (babies born missing all or parts of their brains) in Laredo, Texas; a cluster of multiple sclerosis in El Paso, Texas, and a cluster of brain cancer in Fairfield, Maine.

One in four Americans lives near a Superfund site; studies have shown that children born within a quarter-mile of a Superfund site are at greater risk of birth defects.

And researchers have correlated exposure to lead with substantial decreases in IQ scores at exposure levels half of what the government considers problematic. Significant increases in brain and nervous system cancers, autism-spectrum disorders, and learning and behavioral disorders have been reported in recent decades.

3. The chemical industry has hijacked public health policy in order 1) to ensure that all chemicals are *assumed* safe until proven otherwise, 2) to make it impossible to prove otherwise, and 3) to focus efforts on "managing" risks rather than avoiding them.

Chemicals Are Assumed Safe until Proven Otherwise.

Current policies intended to protect against toxic chemical exposures actually exacerbate each dimension of this problem. For industrial chemicals (meaning chemicals that are not pesticides or pharmaceuticals), *no pre-manufacture testing is required.* Because federal agencies have used their limited authority to request information on some newer chemicals, chemicals that were on the market before current law was established present the bigger problem; by volume, these represent 99 percent of the chemicals in use. So the first problem is that chemicals are assumed safe until proven otherwise, leaving the burden on government agencies with limited resources to assess thousands of chemicals and attempt to prove health effects.

No pre-manufacture testing is required for any industrial chemicals (chemicals that are not pesticides or pharmaceuticals).

"Managing," Rather Than Avoiding the Risk

The second problem is that even when there's credible evidence that harm may occur from exposure to a chemical, current practice relies on assessing and "managing" the risk, rather than avoiding risk where possible. Common sense would dictate that a manufacturer not use a chemical known to cause birth defects in children's toys. But manufacturers have rigged the process to force regulators to first spend years assessing risk, which means guesstimating the relative odds that a chemical's guesstimated toxicity combined with the average person's (usually a middle-aged middle-sized male) guesstimated exposure levels will produce an impact on health. Then regulators attempt to keep the risk to an "acceptable" level.

Phthalates in Children's Toys: An Example

The Consumer Product Safety Commission (CPSC) provided a particularly absurd example with its recent decision not to restrict the use of phthalates in children's toys. The agency did not dispute that the chemicals are toxic or that they are present in children's toys or that they leach out of the toys when children chew on them. But in the agency's assessment, a

The CPSC estimated that most children don't chew on plastic toys for 70 minutes, and so aren't at danger for exposure to phthalates.

child would have to chew on the toy for an average of 70 minutes per day in order to get the level of risk estimated to be unacceptable; based on their observations, the average child does not chew on a plastic toy for that long. What about the children who chew on toys for more than the average child? What happens when the toxicity assessment is revised and lower exposure levels turn out to be dangerous? (The level of lead exposure considered safe is six times lower today than it was several decades ago and recent research shows that it is still not low enough; there is likely no safe level.) This approach to protecting public health defies all common sense.

In order for the EPA to act, they must show that the benefits of the proposed restriction outweigh the economic costs.

In addition, federal agencies' hands are tied even when they have sufficient evidence, and the relevant risk estimates, to restrict or prohibit the use of a chemical. In order for the Environmental Protection Agency to act under the Toxic Substances Control Act (a misnamed law), regulators must show: 1) that the chemical "will present an unreasonable risk" (In the context described above, this is a practically impossible standard.); 2) that the benefits of the proposed restriction outweigh the economic costs; and 3) that the proposed restriction will be less burdensome than other regulations, such as caps on specific pollution sources. When EPA proposed banning asbestos, one of the substances most strongly linked to cancer, a federal judge revealed clearly the flaws in this policy by concluding that the EPA did not have sufficient authority to ban asbestos.

The Toxic Substances Control Act is so weak that a federal judge concluded that it did not give the EPA sufficient authority to ban asbestos

A Policy Vision: Developing a Sane Policy

Developing a rational policy for protecting health and development against toxic chemical exposures might seem daunting when confronted with such an overwhelming problem complicated by such arcane and obtuse policies. But a rational public health policy simply relies on several common-sense principles:

1. The public has a right to know about any chemicals in use, their specific uses, potential threats to health and the environment, and potential exposures. The public also has a right to participate in decisions that could affect health.

2. The government should prohibit use of a chemical if there is significant evidence that it poses serious threats or if potential threats have not been adequately assessed. Manufacturers and users of a chemical bear a burden to assess the potential threats of a chemical and seek government approval for its use.

3. Government should require manufacturers to use safer alternatives where they exist. Where they do not, government and industry should promote development of alternatives. If an alternative does not exist for a chemical that plays an important role in society (e.g. medical supplies), government should only allow minimal use until alternatives are available. Minimizing use of the chemical is always better than trying to control exposures.

4. Government should make policy decisions about chemicals based on maximizing protection of public health and the environment. Specifically, decisions should:
    - be based on the intrinsic hazards (toxicity) of a chemical rather than on the odds of exposure or harm
    - err on the side of protecting health and the environment where there is uncertainty in the evidence
    - be applied to groups of chemicals where the evidence indicates likely similarities among chemicals.

5. Contamination resulting from the use of chemicals should be cleaned up to a level protective of health and restoring any damage to the environment.

6. Government should hold manufacturers and users of chemicals responsible legally, financially, and, to the extent possible, physically for the costs and consequences of the use of toxic chemicals. This includes:
    - bearing the financial burden of testing chemicals,
    - paying for the clean-up of toxic waste sites,
    - taking physical responsibility for keeping products (and byproducts) out of the waste stream, and
    - compensating those whose health has been affected.

Obstacles to Progress

Of course, this vision of a healthier world is more easily described than realized. The primary obstacle is the political influence of the chemical industry, which wields significant power at both the state and federal levels. At the federal level, the American Chemistry Council (ACC), the chemical industry's lobbying group, and its member companies have given $50 million to Congressional campaigns since 1995. ACC spent $30 million on lobbying Congress. ACC represents only a fraction of the U.S. companies who use chemicals; the oil industry makes chemicals and virtually every manufacturing company uses chemicals. Each of these industries spends tens of millions of dollars on lobbying and campaign contributions.

Progress Made to Date (Despite Obstacles)

Despite years of opposition by the chemical industry, public interest advocates have made significant progress toward protecting public health. In 1980, Congress passed the Superfund law (prodded by the crisis at Love Canal, NY), making companies liable for cleaning up toxic waste sties and putting a tax on companies using toxic chemicals that would be used to operate the program and clean up sites where a responsible party could not be found.

But industry opposition made efforts to restrict or ban chemicals nearly impossible. This factor combined with the overwhelming lack of information focus reform efforts on the right-to-know. In the mid 1980s, states passed numerous right-to-know laws. In 1986, Congress created the Toxics Release Inventory, requiring thousands of companies to file annual reports on toxic pollution. In the late 1980s and early 1990s, states passed pollution prevention laws. The most successful required companies to report their use (not just releases) of chemicals and to develop toxics-use reduction plans.

The federal Toxics Release Inventory has been credited with a reduction of more than fifty percent in reported chemical releases.

These initiatives have produced extraordinary results: California's Proposition 65 led some companies to remove chemicals from products rather than put warning labels on them. The federal Toxics Release Inventory has been credited with a more than 50 percent reduction in reported chemical releases. In Massachusetts,

New Jersey firms reported saving $5–8 for every $1 spent on complying with the strict new toxics use reduction law.

which has the nation's strongest toxics-use reduction law, reported releases have declined 90 percent, generation of toxic waste has declined 50 percent, and the use of toxic chemicals has declined 40 percent. Meanwhile, companies saved money: in New Jersey, which has a law similar to Massachusetts, by 1995 firms reported saving $5-8 for every $1 spend on complying with the new law.

Recent Policy Developments and Specific Policy Directions

It is time to launch the next major campaign to protect health, and children's development from toxic chemicals. In the Public Interest Research Groups' (PIRGs) opinion, three specific policy directions require more attention: 1) restricting and banning chemicals known to be hazardous; 2) making assessments of toxicity a condition for continued use of a chemical; and 3) focusing policies on disclosing and restricting chemicals used in consumer products.

The coming months and years may provide an opportunity for a renewed push in these directions. State legislatures have been moving to prohibit several uses of chemicals. A handful of states have banned certain uses of mercury. Washington state has a new program to phase out the releases of about 25 of the most dangerous chemicals. California is close to banning two out of three of the PBDEs.

The European Model

The most significant policy development on the horizon is taking place in Europe. There, policymakers have crafted a proposal to overhaul the regulation of chemicals. A bill in development (and likely to pass) would:

1. Set a timeline by which companies must provide toxicity assessment information on 30,000 chemicals manufactured in quantities of more than 1 ton per year or remove the chemical from the market
2. Reverse the burden of proof: if a chemical is deemed of "high concern" (a category including chemicals with known or probable links to cancer, birth defects, reproductive toxicity, or endocrine disruption), its manufacturer or user must apply for government permission to continue using it.

Moving Forward to Protect Our Future

These policy developments are good news, but sustaining them and transforming them into national progress in the U.S. will require vision and ambition—not only because visionary reform is required, but because the chemical industry is likely to mount a significant effort to stop any new regulation. (The industry is already planning a new advertising campaign expected to cost $40 million dollars per year.) In order to protect our health, the environmental and health communities must come together with a far-reaching national initiative to change the way chemicals are regulated. My initial thoughts on critical strategies include the following:

The *goals* should be two-fold:

1. In the short term, enact "piece-meal" policies, such as bans (or potentially new right-to-know requirements) on specific chemicals, at the state and federal levels, stimulating a nationwide debate in the process.

2. In the long term, enact reforms of overall toxics policies at the state and federal levels.

The strategy should include several elements:

1. The lynchpin of the strategy is to tie various single-chemical campaigns together—with a consistent message and coordinated public education and coalition-building effort—into a nationwide campaign to lay the groundwork for overhauling chemicals policies.

2. Major public education is required, but it must be a message people can relate to. Most people do not ever think about chemicals they might be exposed to (much less obscure policies governing how they are regulated). But they do think about one major exposure route: consumer products. We live in a consumer society and spend much of our day being bombarded with advertisements for one product or another. Polls show that most Americans believe that any product on the market has been tested and approved by the government; they would be shocked to learn that a chemical known to cause reproductive problems is in their children's toys. Public education

around specific products with known toxic chemicals could be a major strategy for building public support.

3. Ambitious coalition building will be critical. Such a campaign will require multiple spokespeople and supportive constituencies. These include affected constituencies in addition to learning and developmental disabilities advocates: breast cancer advocates, medical groups, and other disease-specific groups. In addition, a supportive network of scientists, researchers, and doctors will provide a credible voice and limit the industry's ability to portray public interest advocates as techno-phobic or "anti-progress." Another key constituency with which coordination will be critical is labor unions in order to limit efforts to frame the debate as one of "jobs vs. the environment."

This proposed effort is ambitious. It will require significant time, energy, and resources. But it is hard to imagine a more important investment.

8. Framing a National Blueprint for Health Promotion and Disability Prevention

Appendix 1 contains additional recommendations from the Work Groups.

The participants of the Wingspread National Summit on Pollution, Toxic Chemicals and Mental Retardation met to share their knowledge on research, services, policy, and supports, and to create their vision for the future. This chapter presents the ideas that emanated from this Summit and that were approved by group consensus (rated as most important by most participants). While framing a blueprint for further action that will examine the link between environmental toxicants and pollution, and mental retardation and developmental disabilities, these ideas are intended to be only a starting point for a vigorous national dialogue and agenda.

Appendix 1 contains additional recommendations from the Work Groups.

1. Vision

The environmental health and developmental disabilities communities representatives have a shared vision of a world:

- Where people know that they are safe, that their products are safe, that their communities are safe, and that service systems and policies are protecting them.
- Where the overall health of all people is improved, and the quality of life of those who are living with developmental disabilities is protected.
- That is free from developmental disabilities and other health problems caused by, or made worse by environmental exposures.
- Where all people (women, children, families, people with disabilities, people who work in various industries, people who work in the environmental field, corporate officers and staff, shareholders, and regulators) are considered

The Wingspread participants owe a debt of gratitude to the John Merck Fund for sponsoring the Wingspread Summit and to the Johnson Foundation for hosting this special event.

"interested parties" in improving health and regulating toxicants.

2. Guiding Principles

The environmental health and developmental disabilities communities representatives should use the following principles to guide their work on this important topic:

- The American people expect to be out of harm's way from environmental neurotoxicants.
- People expect to know if there is something in the air, water, or in commercial products that may harm them.
- People expect their government systems and policies to promote and ensure their safety and the safety of their communities.
- Eliminating potentially harmful chemicals from our environment is a prerequisite to ensuring the optimal development of all children and adults with developmental disabilities.
- Society has the responsibility of eliminating environmental contributors to mental retardation and related developmental disabilities.
- People have a right to expect industrial producers of goods and services to be good corporate citizens.
- An interdisciplinary approach to addressing the issues of environmental toxicants and developmental disabilities is critically important.
- Protections against harmful toxicants should be created to protect the most vulnerable in our society so that *all* people will be protected.
- People with developmental disabilities need to understand, support, and participate in establishing the research design, agenda, and oversight of this important issue.

- Precautionary actions should be taken to protect the health of those with developmental disabilities and future generations.

3. Basic Rights

The environmental health and developmental disabilities communites representatives assume that the following are basic rights of all Americans:

- American citizens have the right to expect that their government is protecting them from harmful pollutants, and is disclosing important information about pollution and toxic chemicals.
- Every adult has a right to a healthy work environment (including sheltered work environments).
- Men and women have a right to expect that their health is not being compromised by toxicants in the environment and their homes, so that they can be healthy for themselves, their children, and their families.
- Every child has a right to a healthy school environment that is clean and in good repair.
- All people with developmental disabilities have the right to participate fully and make informed choices about decisions that affect their health, including services, policies, and research.
- People with developmental disabilities have the right to pursue their lives in environments free from potentially harmful chemicals.

4. What We Know

The environmental health and developmental disabilities community representatives believe that the following are known truths or scientifically proven facts:

- We know that developmental disabilities are widespread and create challenges for individuals, their families, and society.
- We know that certain chemicals can cause or contribute to developmental disabilities.
- We know that the developing brain is especially sensitive to damage.
- We know that certain environmental agents (mercury, lead, PCBs, alcohol, and some pesticides) have been proven to adversely impact the developing brain.
- We know that tens of thousands of chemicals—individually or in combination—in the air we breath, the food we eat, the water we drink, and the products we buy have not been evaluated for their potential impact on developmental disabilities and on human health.
- We know that a wide variety of social factors (educational level, poverty, nutrition) interact with other environmental exposures to increase their adverse impact.
- We know that certain chemicals can cause or contribute to the occurrence of mental retardation and related developmental disabilities.
- We know that, while continued research is necessary, we cannot wait for a thorough assessment of all potential hazards before acting to protect the health and wellbeing of those with developmental disabilities and future generations.

5. What We Suspect to Be True

The environmental health and developmental disabilities communities representatives estimate that the following are true:

- We suspect that mixtures/interactions of agents are uniquely and unpredictably harmful.
- We anticipate, based on current understanding, that chemicals—individually or in combination—will be

identified as causal agents in the onset of developmental disabilities.

- We estimate that a variety of risk factors, including chemical exposures, poor nutrition, and poverty will interact to exacerbate the impact of developmental disabilities.

- We estimate with confidence that some people with developmental disabilities are especially sensitive to certain environmental exposures (e.g., Rhett syndrome and breathing difficulties, fetal alcohol syndrome and a noisy environment, etc.).

6. Research

The environmental health and developmental disabilities communities representatives support the following statements concerning research:

- An aggressive research agenda to fill the gaps in knowledge about environmental causation to developmental disabilities should be pursued.

- Once the evidence of harm is established, funding agencies should not continue investing in research to establish the lowest safe threshold, but spend scarce research dollars investigating and researching suspected toxicants for which little or no data is available

- Government and private organizations should facilitate increased collaboration between the environmental health and developmental disabilities research communities.

- Researchers and institutional review boards should be educated about people with developmental disabilities and encouraged to include them as participants in research protocols.

- The National Institutes of Health should include people with MR/DD in exposure studies.

- The Centers for Disease Control and Prevention should include people with MR in biomonitoring and body burden studies.

- People with developmental disabilities need to understand, support, and participate in research agenda, design, and oversight.

- People with developmental disabilities and their families should be included in research study design and implementation (in sufficient numbers to generate reliable knowledge), and in decision-making regarding their lives.

- The families and people with intellectual disabilities should be supported to participate in the design and implementation of the National Children's Study (NCS). (NCS is a longitudinal regulatory toxicology study using 100,000 children.)

- Effective mechanisms to integrate surveillance and biomonitoring data systems should be explored.

7. Government's Responsibility: Laws and Regulations

The environmental health and developmental disabilities communities believe the federal, state, and local governmental entities have the following obligations to their citizens:

- Government has the obligation to protect its citizens from harmful pollutants, and to disclose information to them about harmful pollutants.

- Government agencies and their regulations and standards concerning environmental health should be more responsive to the latest science, scientific methods, technology, and research.

- The regulatory paradigm should be changed so that the burden of proof for establishing safe levels of chemicals and toxicants shifts to the producing industry once the evidence of harm is established.

- The U.S. should consider adopting the European REACH (Registration, Evaluation and Authorization of Chemicals) approach and also include endocrine disruptors.

- Untested chemicals must carry a label telling consumers that they have not been tested and may not be safe. (A "use at your own risk" label.)

- Questions for candidates at all levels of government (local, state, and national) on chemical policy reform and developmental disabilities should be formulated and asked.

Federal Agencies

- The National Institutes of Health should include people with MR/DD in chemical exposure studies.

- The Centers for Disease Control and Prevention should include people with MR in biomonitoring and body burden studies.

- The Public Health Service (PHS), Surgeon General, Health Resources and Services Administration (HRSA) should extend the work on the Health Disparities in People with MR Study to include new statements and workshops on this issue, and explore surveillance and biomonitoring data systems integration.

- The Surgeon General should commission a report to examine health disparities and Public Health Service concerns to determine if they are related to toxic chemicals.

- The Environmental Health Sciences Centers (EHSC) and the National Institute on Child Health and Development (NICHD) should coordinate and cooperate more on environmental and DD issues. Our collaborative will advocate for an administrative interagency agreement to make this happen.

- The families and people with intellectual disabilities should be supported to participate in the design and implementation of the National Children's Study (NCS). NCS is a longitudinal toxicology study using 100,000 children.

- American Building Codes (BOCA) and other related professional standards should be revised to focus on the

inhabitants of the buildings rather than on the building structures by promoting health, and allowing for consumer/public interest input in the setting of such standards.

- Government regulations and standards related to environmental health must be current with the latest research, technology, and best practices (Toxic Substances Control Act [TSCA], Occupational Safety and Health Act [OSHA], Federal Insecticide, Fungicide, and Rodenticide Act [FIFRA], etc.).

- All third party accreditation and Medicaid certification reviews of DD facilities (including nursing homes) should include an environmental review for individuals with developmental disabilities. All National Institutes for Occupational Safety and Health (NIOSH), Occupational Safety and Health Administration, and Council on Accreditation of Rehabilitation Facilities (CARF) standards should pertain to workshops. Nursing Homes should also be included in the review process.

- The Centers for Disease Control and Prevention should include neurotoxicants in their biomonitoring project, and they should expand and enhance the process of surveillance for developmental disabilities.

- The Centers for Disease Control and Prevention should expand and enhance the process of DD surveillance at CDC's Agency for Toxic Substance Registry (ATSDR).

- The Environmental Protection Agency should complete its call-in of developmental neurotoxicology data for 140 pesticides.

- More coordination and cooperation is needed between the Community Environmental Health Resource Centers (CEHRC), the Environmental Health and Safety Committees, and the Mental Retardation/Developmental Disabilities Research Centers (MRDDRC) at all levels. This coordination and cooperation should be mandated from the highest levels of federal government.

- Right-to-know (RTK) materials about indoor and outdoor environmental hazards must be translated into understandable English and be made available in real time. (They should apply across the board to government-

mandated RTK materials like Material Safety Data Sheets or Toxic Release Inventory, but also private sources as EARTH911.org, SCORECARD, Ablelink.)

- Self-advocates (people with developmental disabilities) and their families need to have an independent agency or entity to call for information relating to "right to know" policies

8. Collaboration

The environmental health and developmental disabilities communities will work together to:

- Facilitate increased collaboration between the environmental health and developmental disabilities research communities.
- Explore our non-profit and foundation collaborative influence to advance this agenda.
- Build bridges between federal, state, and local levels related to community-based environmental health and developmental disabilities organizations to enhance policy-making impact and implementation activities.
- Coordinate and connect CEHRCs, EHSCs, and MRDDRCs.
- Incorporate the environmental agenda into the developmental disabilities governmental affairs agenda including the annual multi-organization Seminar.
- Frame questions for candidates at all levels of government on the interplay between chemical policy and developmental disabilities.
- Identify and cultivate spokespeople from the DD community to carry the environmental health message in the near term.
- Invite and include speakers on environmental health at DD national meetings/conventions, and include relevant articles in DD publications.

- Create a listserve and other means of communicating so that the Wingspread dialogue can continue.
- Create ad hoc work groups to move the agenda forward.
- Reconvene in Washington for a follow-up meeting.
- Convene the LDDC in DC to educate Congress and the federal agencies about this important agenda.
- Identify and cultivate long-term funding and foundation support to continue to advance this agenda.

9. Education and Dissemination

The environmental health and developmental disabilities communities will work together to:

- Develop a communications strategy/plan to communicate Wingspread outcomes to key stakeholders and government decision makers.
- Disseminate information from this summit to people with developmental disabilities and self-advocate groups, families, practitioners, service providers, medical professionals, educators, policy makers, etc.
- Educate researchers and institutional review boards about the need to include people with developmental disabilities as participants in research protocols.
- Create a module for an on-line training program about environmental hazards and their effects on people with DD for DD staff and others who support people with developmental disabilities.
- Build a "library" of practical resources that is accessible by people who live in group homes and other community living arrangements.

Appendix 1. Work Group Recommendations

Work Group Recommendations

After reading the papers and hearing the presentations, the Summit participants met in Work Groups to formulate solutions to the issues presented. Below are some of the ideas and recommendations that came out of these Work Groups. These items were not subjected to the consensus process, but may be helpful in continuing the dialogue toward a national Blueprint for Action.

Research

Research the Effects of Chemicals on Health and on Developmental Disabilities

1. Research the association between exposure to neurotoxicants and their contribution to causing developmental disabilities.

2. Research the fetal origins of adult diseases.

3. Research co-morbidity issues.

4. Research the total environmental risk factors for school facilities.

5. Research a broader set of risk factors, such as poverty and nutrition, which interact with environmental exposures to known and suspected neurotoxicants to impact health and development.

6. Research the effects of real world *combined* chemical products (rather than focus exclusively on single chemicals) that may be, but are not yet proven to be, neurotoxicants. Given that it is impossible to study all chemicals in combination, choose chemicals that the public might commonly come in contact with in combination—such as

mercury and PCBs in fish, or off-the-shelf pesticides—in order to prioritize the research agenda. This may demonstrate that many mixtures may have additive or synergistic health impacts.

7. Conduct exposure assessments of those chemicals that have not been tested relative to the toxicogenomic research. In other words, structure new assessments to respond to toxicogenomic research. (Identify chemicals that interfere with gene expression related to DDs).

8. Use interdisciplinary approaches to evaluate multiple levels of potential toxicants to develop standardized assessment batteries for testing behavioral and central nervous system effect of toxicants.

9. Research alternatives—replacements for implicated, but not necessarily proven, neurotoxicants.

10. Conduct health tracking studies which include developmental disability and neurological outcomes.

11. Conduct consistent biomonitoring to gather long-term human data on exposures to potential neurotoxicants. Information is needed on actual exposures.

12. Conduct animal studies to determine toxicological effects on the developing brain. CDC should look at a broader range of chemicals including more neurotoxicants in the list of examined substances.

13. Conduct epidemiological studies and research the long-term body burden—bio-monitoring—including level of toxicants, in whom, where, what, etc. Studies should include people with DDs.

14. Once the evidence of harm is established, don't prioritize research establishing the "safe level beyond a doubt," but spend scarce research dollars examining potentially dangerous chemicals about which we have little or no data.

15. Establish a better connection between the funders of developmental disabilities research and environmental research. (NIH and NICHD fund *both* developmental disabilities research through MRDDRCs *and* chemical and neurotoxicant research through EHSCs—sometimes at the same universities. These institutes and centers should

communicate with each other and conduct joint research studies to further this agenda. The NIH Commissioner should make it a priority to facilitate this collaboration.)

Research the Particular Effects of Chemicals and the Environment on People with Mental Retardation and Developmental Disabilities

1. Research the impacts that exposure to chemicals may have on people with MR/DD such as how chemicals in the air, water, and food may impact this group of people in ways that may be different than or similar to the general population. Suggestion: start with the school setting.

2. Research the potentially heightened sensitivities of those with DDs to environmental exposures (e.g., by using animal models and co-morbidities), and identify interventions to improve their quality of life. Include families and care providers. Research whether children with DDs have special environmental needs or conditions pertaining to acoustics, light, chemicals, onother issues. Is there a greater vulnerability, risk, or exposure? Is there less protection for people with DDs? Are there early interventions that would make it easier for people with DDs across their lifespans?

3. Examine the environmental characteristics of facilities in which people with DDs live, learn, work, and play—especially schools and sheltered workshops—and determine the environmental risk factors.

4. Research building and other codes and standards relating to noise, light, chemicals, etc., that may affect children with DDs. Communicate any needed modifications to the appropriate industries, services, and parents. Standards for building codes are now largely developed by various professional standards groups. Consumers and public interest organizations, especially those representing children, need a proportional voice in creating standards and codes.

5. Research the lifelong impact of having a disability and living in a polluted environment (longitudinal studies and epidemiological studies). Pay special attention to children growing up in poverty exposed to environmental pollutants.

6. Encourage research to support the development of appropriate communication materials for caregivers and those with DDs. What would be most effective and useful?

7. Establish a health tracking system for developmental disabilities.

People with DD Should Be Involved in Research

1. People with developmental disabilities have the same right as other Americans to know they are safe and to have the information necessary to make their own choices.

2. People with DD and their families should be involved in planning all research initiatives and should be able to participate in research studies and their design.

3. Research samples must be large enough to include representative numbers of people with DD.

4. Relevant environmental and health studies should be identified to make sure that the DD constituency is included in these studies.

Research the Economic Impacts

1. Examine the economic impact that environmental exposures have on developmental disabilities.

Research Public Policy Issues

1. Research public policy issues, i.e., what knowledge is most worth having, what is the best way to affect change, how to ensure that good regulations are made. Examine how toxicological data and biomonitoring linked to health outcomes can be used to improve social policy.

Research Ways to Communicate Research Findings

1. Research communication techniques for changing behavior and research and methodologies for communicating risks.

2. Research how to effectively communicate environmental hazards to the DD population and those who serve them so that they can protect themselves.

3. Ensure accountability for communicating research results to people with DD.

Working For Healthy Homes, Communities, and Lives

Improve the Environment

1. Develop and promote best practices for healthy indoor environments (containing and abating lead, radon, asbestos, etc., and reducing exposure to paint, cleaning agents, pesticides, chemicals, etc.).

2. Set a primary goal of healthy environments for all schools.

3. Promote environmental monitoring of day care facilities and schools, (i.e., "bucket brigade" volunteers who collect and monitor air samples in schools) as a community activist tool.

4. Develop occupational health standards based on environmental health research for sheltered workshops and other places where people with DDs spend time.

Institute Prevention Measures

1. Employ environmental interventions to decrease exposure to toxicants.

2. Institute universal prenatal care in an attempt to decrease low birth weight and prematurity from smoking, alcohol, poor nutrition, and other environmental factors.

3. Standardize maternal screening for lead, mercury, and thyroid problems (clinical and subclinical hypothyroidism). For thyroid screening, start with a pilot study to determine incidence.

4. Implement universal screening for lead in children and adults.

5. Employ workplace and occupational safety measures to decrease exposure to lead, mercury, pesticides, and other toxicants. Encourage noise control.

6. Include individual environmental health assessments as part of the multidisciplinary review process for IDEA and Section 504.

7. Gather and publicize anecdotes and personal stories to raise awareness in order to move policy, legislation, and research.

Educate People about the Risks

Determine the target audiences for educational materials: parents, caregivers, self-advocates, pregnant women, educators, physicians, health providers, policy makers, Congress, the Administration on Developmental Disabilities (ADD), and others.

Educate the Public

1. Clarify and hone the messages we want people to know and the actions we want them to take.

2. Develop more community-based education.

3. Integrate environmental health information into existing public information materials.

4. Provide information that will lead to the prevention of DDs and better public policies to ensure safety.

5. Educate women about folic acid supplementation, FAS, mercury, and other potential risks. Promote alcohol-free holidays during pregnancy.

6. Promote nutritional intervention and enhancement.

7. Promote integrated pest management control for homes.

8. Educate people about restricting their patterns of consumption of fish to reduce mercury levels (based on local and national data).

9. Educate people about brominated flame retardants and alternatives.

10. Educate the public about household hazardous waste (recycling and education programs) and hazardous household products.

11. Design training curriculums to inform job coaches for people with DDs.

Educate Medical Personnel

1. Train health care professionals about environmental hazards and toxicants and their health risks.

2. Identify education and communication networks that have a mission of educating health care professionals.

3. Request that health care providers incorporate information into health care protocols.

4. Request that medical education programs educate doctors and residents about this topic. Provide materials that can be integrated into their curriculum. (Physicians read journals that are most pertinent to them. There is a template for physicians' education in *In Harm's Way*.)

Educate Parents

1. Train parents in environmental health practices for the home and the school. Seek funding for educational projects and mechanisms.

2. Provide parents with educational materials concerning environmental toxicants and their possible effect on their children with DDs. (Now parents are being told to use IDEA and 504 to get help for a child presenting with DDs.)

Educate the Government

1. Explore collaboration between NIH, EHSCs and MRDDRCs. This is the key to educating health professionals. Discuss their priorities and protocols and make additions to RFPs, where possible—with particular emphasis on community-based projects and educating local health professionals.

2. Educate NIH, EHSC, NICHD, and MRDD centers about the need for more health education on this topic, the need for an integrated approach, and the need to educate health care educators and caregivers.

3. Educate policymakers about these issues. Include self-advocates in this education effort.

Institute Regulatory and Policy Changes

1. Make existing and most current research data available to regulators.

2. Change regulatory philosophies and practices that would better protect the public. The paradigm should be to protect human health as a priority when companies create new chemicals/products.

3. Establish right-to-know labeling laws that would be appropriate/relevant to helping people with DDs, caregivers, and others determine what is in a product (specifically, known or suspected neurotoxicants).

4. Create a centralized database on products (with "people friendly" language and symbols) that would be easily readable and accessible to caregivers and those with DDs, so that they can feel empowered and make healthier choices.

5. Develop educational materials that are "people friendly." Design trainings for caregivers and people with disabilities.

6. Seek funding from Congress for the Department of Education to make grants to states for healthy schools design programs and to implement the Healthy and High Performance Schools Act (HHPSA) of No Child Left Behind.

7. Ask EPA to set indoor air quality standards.

8. Push legislation that would allocate funding for health tracking and research—specifically a pilot study undertaken collaboratively by EH and DD research centers.

Additional Recommendations

Potential partners in research should include:

- Government agencies: National Institute on Child Health and Development (NICHD), National Institute on

Environmental Health Sciences (NIEHS), Centers for Disease Control (CDC)

- University Centers of Excellence in DDs
- University Centers for Environmental Health Research
- Health researchers (co-collaborators)
- People with DDs and their families
- Advocacy organizations (DD and environmental health)
- Relevant health professionals (pediatricians, OB-GYNs, nurses, etc.)
- Public health officials
- National Environmental Education and Training Foundation (NEETF)
- Community foundations
- Foundations focused primarily on DDs and/or EH
- Faith-based groups
- PTAs
- Teachers
- "Green" businesses

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Appendix 3. Abbreviations

Organizations

AAMR	American Association on Mental Retardation
ACC	American Chemistry Council
ADD	Administration on Developmental Disabilities
ANCOR	American Network of Community Options and Resources
APHA	American Public Health Association
ATSDR	Agency for Toxic Substances Disease Registry
AUCD	Association of University Centers on Disabilities
BOCA	Building Officials and Code Administrators International
CARF	Council on Accreditation of Rehabilitation Facilities
CDC	Centers for Disease Control and Prevention
CEHC	Children's Environmental Health Campaign
CEHRC	Community Environmental Health Resource Center
CPSC	Consumer Product Safety Commission
DDRC	Developmental Disabilities Research Consortium
DOE	Department of Education
DPH	Departments of Public Health
EHSC	Environmental Health and Safety Committees
EPA	Environmental Protection Agency
GAO	Government Accounting Office
HHPSA	Healthy and High Performance Schools Act of the No Child Left Behind Act
HRSA	Health Resources and Services Administration
IASSID	International Association for the Scientific Study of Intellectual Disability
ICEH	Institute for Children's Environmental Health
IRB	Internal Review Board
LDDA	Learning Disabilities Association of America
LDDC	Learning and Developmental Disability Consortium
MRDDRC	Mental Retardation/Developmental Disabilities Research Centers
NAS	National Academy of Sciences
NCBDDD	National Center on Birth Defects and Developmental Disabilities
NCHS	National Center for Health Statistics

NEA	National Education Association
NEETF	National Environmental Education Training Foundation
NET	National Environmental trust
NICHD	National Institute on Child Health and Development
NIEHS	National Institute on Environmental Health Sciences
NIH	National Institutes of Health
NIOSH	National Institute for Occupational Safety and Health
NRC	National Research Council
OMB	Office of Management and Budget
OSHA	Occupational Safety and Health Administration
OTA	Office of Technology Assessment
PHS	Public Health Service
PIRGs	Public Interest Research Groups
PSR	Physicians for Social Responsibility
PTA	Parent Teacher Association
RTC	Research and Training Centers
SABE	Self Advocates Being Empowered
The Arc	The Association for Retarded Citizens
UCEDD	University Centers of Excellence in Developmental Disabilities
UCP	United Cerebral Palsy Association
WHO	World Health Organization

Laws

504	Section 504 of the Rehabilitation Act
ADA	Americans with Disabilities Act
FIRFA	Federal Insecticide, Fungicide, and Rodenticide Act
IDEA	Individuals with Disabilities Education Act
OSHA	Occupational Safety and Health Act
TSCA	Toxic Substances Control Act

Other

CP	Cerebral palsy
DD	Developmental disabilities
DNT	Developmental neurotoxicity testing
FAE	Fetal alcohol effects
FAS	Fetal alcohol syndrome
IQ	Intelligence quotient
MR	Mental retardation
NCS	National Children's Study
NT	Neurotoxicant or neurtoxicology

OP	Organophosphates
PBDE	Polybrominated diphenyl ethers
PCB	polychlorinated biphenols
REACH	Registration, Evaluation & Authorization of Chemicals
RFP	Request for proposal
RTK	Right to know

Appendix 4. Resources

Web Sites

MR/DD Web Sites

www.aamr.org (American Association on Mental Retardation)

www.ancor.org (American Network of Community Options and Resources)

www.aucd.org (Association of University Centers on Disabilities)

www.thearc.org (The Arc of the United States)

Environmental Web Sites

www.checnet.org (Children's Health Environmental)

www.cehn.org (Children's Environmental Health Network)

www.chej.org (Center for Health, Environment and Justice)

www.environet.org (National Environmental Trust)

www.EnvironmentalHealthNews.org

www.healthyschools.org (Healthy Schools Network)

www.iatp.org (Institute for Agriculture and Trade Policy)

www.iceh.org (Institute for Children's Environmental Health)

www.noharm.org (Health Care Without Harm)

www.OurStolenFuture.org

www.pirg.org (Public Interest Research Group)

www.ProtectingOurHealth.org

www.psr.org (Physicians for Social Responsibility)

www.scorecard.org (Environmental Defense Fund)

Government Web Sites

www.acf.dhhs.gov/programs/add (Administration on Developmental Disabilities)

www.atsdr.cdc.gov/hazdat.html (Agency for Toxic Substances and Disease Registry)

www.cdc.gov/ncbddd (National Center on Birth Defects and Developmental Disabilities Centers for Disease Control and Prevention)

www.epa.gov/pesticides (U.S. EPA Pesticide Program)

www.mchb.hrsa.gov (Maternal and Child Health Bureau)

www.nichd.nih.gov (National Institute of Child Health and Human Development)

www.niehs.nih.gov (National Institute on Environmental Health Sciences)

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