Pollution, Toxic Chemicals, and Mental Retardation

Framing A National Blueprint for Health Promotion and Disability Prevention

Proceedings of A National Wingspread Summit

Executive Summary

M. Doreen Croser and Margaret Seiter, editors

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

Contents

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, has 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:
Sheryl White-Scott, MD
Elise Miller, MEd
Ted Schettler, MD, MPH
Philip W. Davidson, PhD
Pete Myers, PhD
Deborah E. Cohen, PhD
Claire L. Barnett, MBA
David Wallinga, MD
Jeremiah Baumann

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.

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

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 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

This Executive Summary summarizes key issues and ideas presented at the Wingspread Summit on Pollution, Toxic Chemicals, and Mental Retardation. The complete report includes the Executive Summary plus 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) a glossary of terms, and 4) a list of resources.

The complete 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/ToxinsandMental Retardation.

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 of the complete report contains a framework for a National Blueprint for Action. The complete report can 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 of the entire report "Pollution, Toxic Chemicals, and Mental Retardation: Framing a National Blueprint for Health Promotion and Disability Prevention."

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 following 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.

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

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.

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 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.

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.

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.

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*—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.

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 health effects. 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 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 6 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, and 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 the fetus, 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 more 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 effects 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 that (1) 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 the authority. 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(s) may simply decline to utilize the authority that they have.

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 on the public.

There are many known toxicants with probable links to cancer, birth defects, or our 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's 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 in general.

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 in the full report 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, ground-breaking 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. Participants

Len J. Abbeduto, PhD
Associate Director for Behavioral Sciences
Waisman Center
University of Wisconsin-Madison
Madison, WI

Ansley Bacon, PhD
Executive Director
Westchester Institute of Human Development
New York Medical College
Valhalla, NY

Claire L. Barnett, MBA
Executive Director
Healthy Schools Network, Inc.
Albany, NY

Jeremiah Baumann
Director
State Public Interest Research Groups
Washington, DC

Coleen Boyle, PhD
Associate Director for Science
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Deborah E. Cohen, PhD
Director
Office of Prevention
Department of Human Services
State of New Jersey
Princeton, NJ

M. Doreen Croser
Executive Director
American Association on Mental Retardation
Washington, DC

Philip W. Davidson, PhD
Professor of Pediatrics and Psychiatry
University of Rochester Medical Center
Rochester, NY

Sharon Davis, PhD
Director of Professional and Family Services
The Arc of the United States
Silver Spring, MD

Cecilia T. Davoli, MD, MPH
Developmental Pediatrician
Pediatric Environmental Health Specialist
Kennedy Krieger Institute
Baltimore, MD

Allen Dearry
Associate Director
Division of Research, Coordination, Planning, and Translation
National Institute on Environmental Health Sciences
Research Triangle Park, NC

Steven M. Eidelman
Executive Director
The Arc of the United States
Silver Spring, MD

Michael J. Friedlander, PhD
Director
Civitan International Research Center
University of Alabama at Birmingham School of Medicine
Birmingham, AL

James F. Gardner, PhD
Chief Executive Officer
The Council on Quality and Leadership
Towson, MD

Ruth Hennig
Executive Director
The John Merck Fund
Boston, MA

Andy Igrejas
Director
Children's Environmental Health Campaign
National Environmental Trust
Washington, DC

George Jesien, PhD
Executive Director
Association of University Centers on Disabilities
Silver Spring, MD

Susan West Marmagus, MPH
Director
Environment and Health Programs
Physicians for Social Responsibility
Washington, DC

Annette C. McGuire
State Director
Mid-Atlantic Human Service Corporation
Pikesville, MD

Joseph P. Meadours
Director of Consumer Empowerment
Mental Health and Mental Retardation
State of Alabama
Montgomery, Alabama

Elise Miller, MEd
Executive Director
Institute for Children's Environmental Health
Freeland, WA

Teresa Moore
People First of Arizona
Phoenix, AZ

Pete Myers, PhD
Chief Executive Officer
Environmental Health Sciences
Crozet, VA

Wendy Nehring, PhD
Associate Dean of Academic Affairs
Associate Professor, College of Nursing
Rutgers, The State University of New Jersey
Newark, NJ

Tia Nelis
Self-Advocacy Specialist
Research and Training Center on Aging and Disability
Institute on Disability and Human Development
University of Illinois
Chicago, IL

David M. O'Hara
Associate Director
Westchester Institute of Human Development
School of Public Health
New York Medical College
Valhalla, NY

Renee L. Pietrangelo, PhD
Chief Executive Officer
American Network of Community Options and Resources
Alexandria, VA

Anna Prabhala
Publications Associate
American Association on Mental Retardation
Washington, DC

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

Peggy Seiter
President
Seiter Vaughn Communications
Herndon, VA

Sue E. Swenson
Executive Director
Joseph P. Kennedy, Jr. Foundation
Washington, DC

Cathy Ficker Terrill
President and Chief Executive Officer
Ray Graham Association for Individuals with Disabilities
Elmhurst, IL 60126-4327

Beth Terrill
Self Advocate
Elmhurst, Il

David Wallinga, MD, MPH
Co-Director
Institute for Agriculture and Trade Policy
Minneapolis, MN

Sheryl N. White-Scott, MD
Director
St. Charles Developmental Disabilities Program
St. Vincent's Catholic Medical Center
Sister Thea Bowman Family Health Center
Brooklyn, NY

The Johnson Foundation

Christopher Beem
Program Officer
Democracy and Community, Family
The Johnson Foundation
Racine, WI

Linda Stengel
Conference Support Specialist
The Johnson Foundation
Racine, WI

Boyd H. Gibbons, III
President
The Johnson Foundation
Racine, WI

Sarah L Mazur
Wingspread Fellow
Carleton College
Grand Rapids, MI