

Impact of FERPA on Childhood Developmental Disabilities Tracking: One State's Experience

Elaine T. Krueger, Director
Environmental Toxicology Program
Center for Environmental Health
Massachusetts Department of Public Health

Elaine.Krueger@state.ma.us

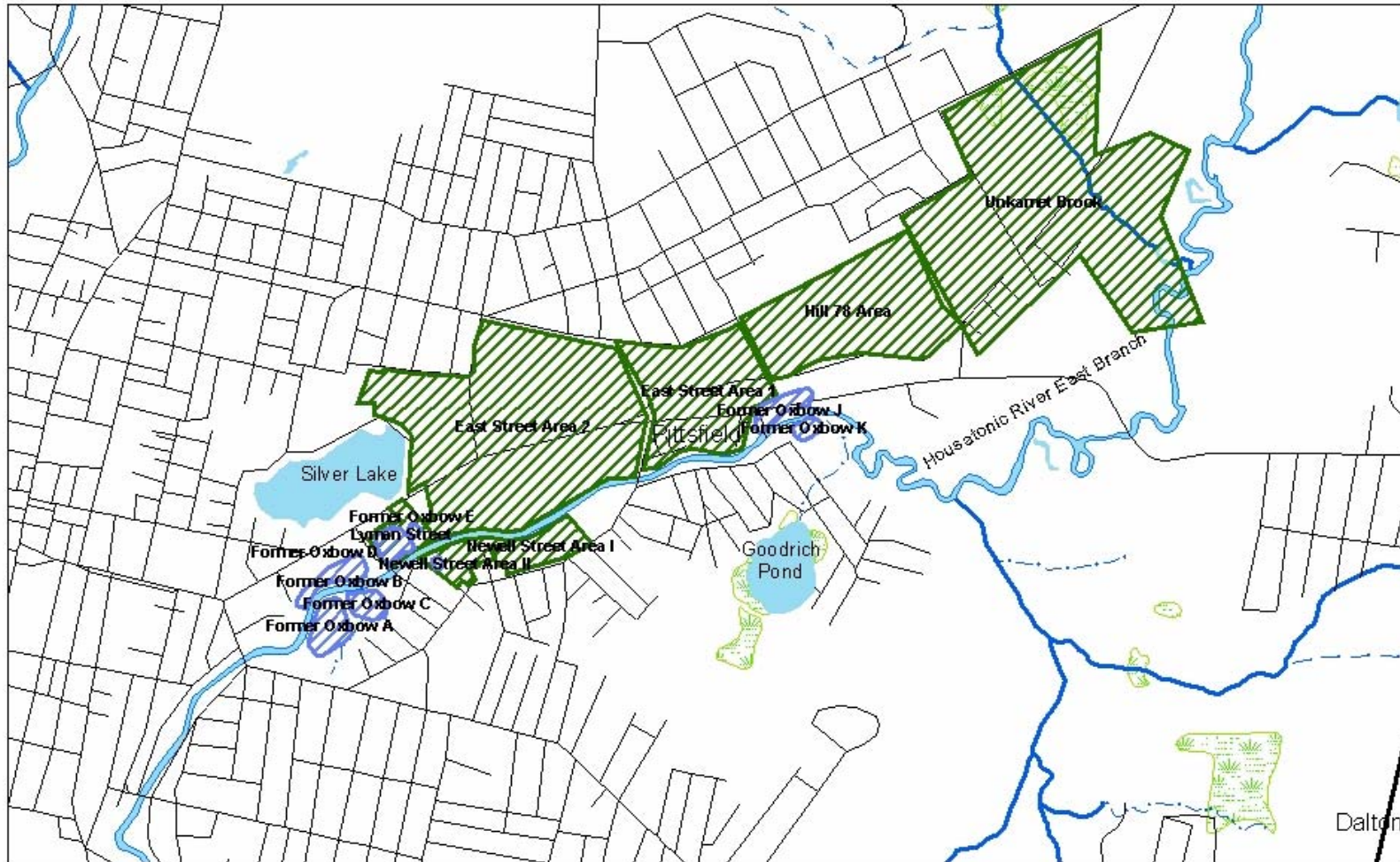
March 28, 2005

Project Goal

- Track developmental disabilities in children and link to polychlorinated biphenyl (PCB) contaminant data in Berkshire County in order to determine possible unusual patterns that may warrant analytical study

Developmental Disabilities and PCBs

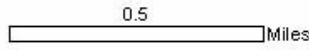
- Strong and accumulating evidence suggests that the interaction of genetic, toxicologic, and social factors is responsible for the development of developmental disabilities such as cognitive and behavior deficits
- PCB exposure has been found to affect neurodevelopment in infancy and childhood
- Prenatal PCB exposure at background levels has been associated with deficits in cognitive functioning

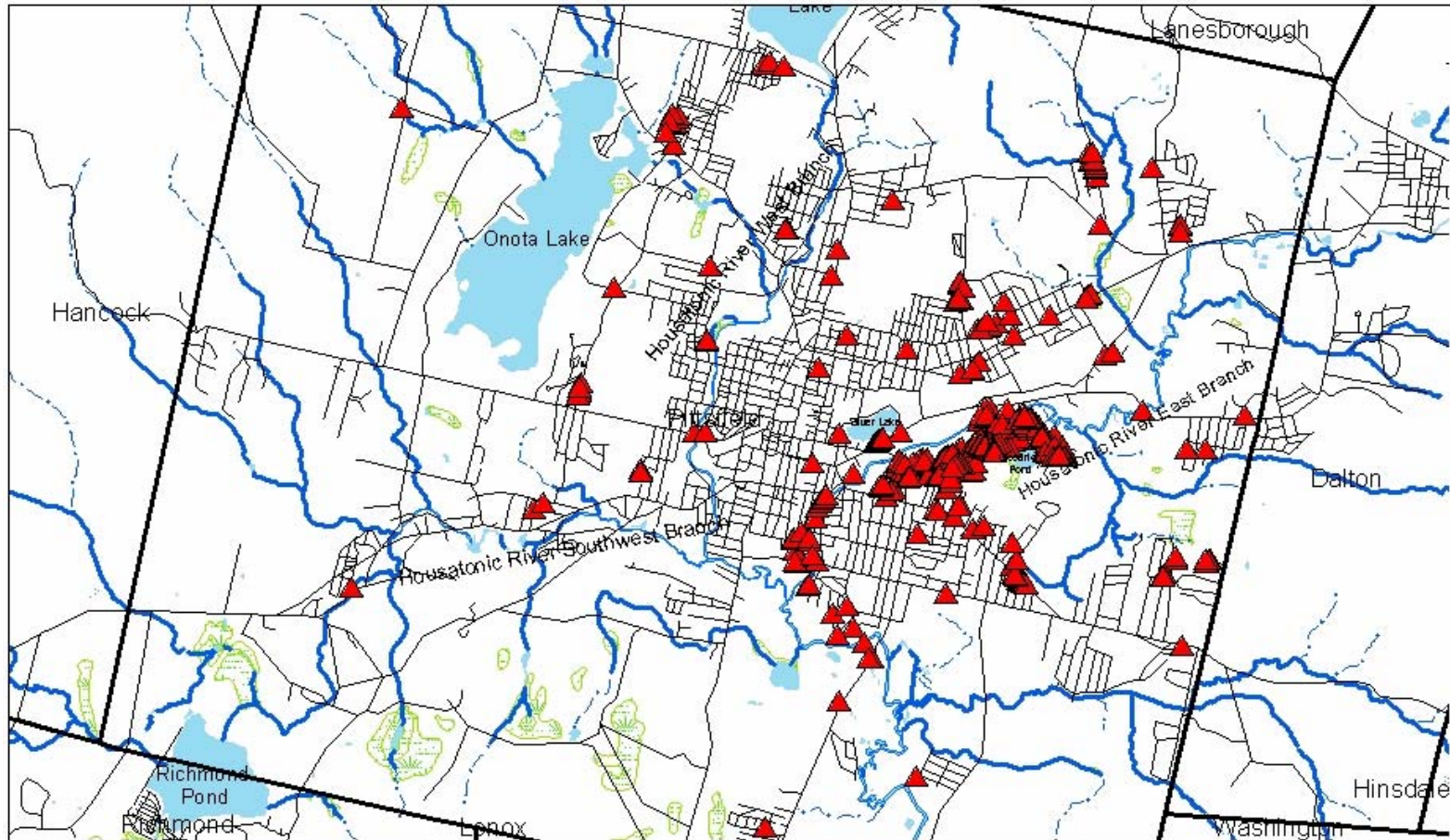


Legend

- | | |
|--------------------------|--------------|
| Massachusetts_Towns | Water Bodies |
| Berkshire_County_Streets | Flat |
| GE Sites | Wetland |
| Former Oxbows | River |
| Rivers/Streams | Lake/Pond |
| River/Stream | |
| Intermittent Stream | |

General Electric Sites, Pittsfield, MA





Legend

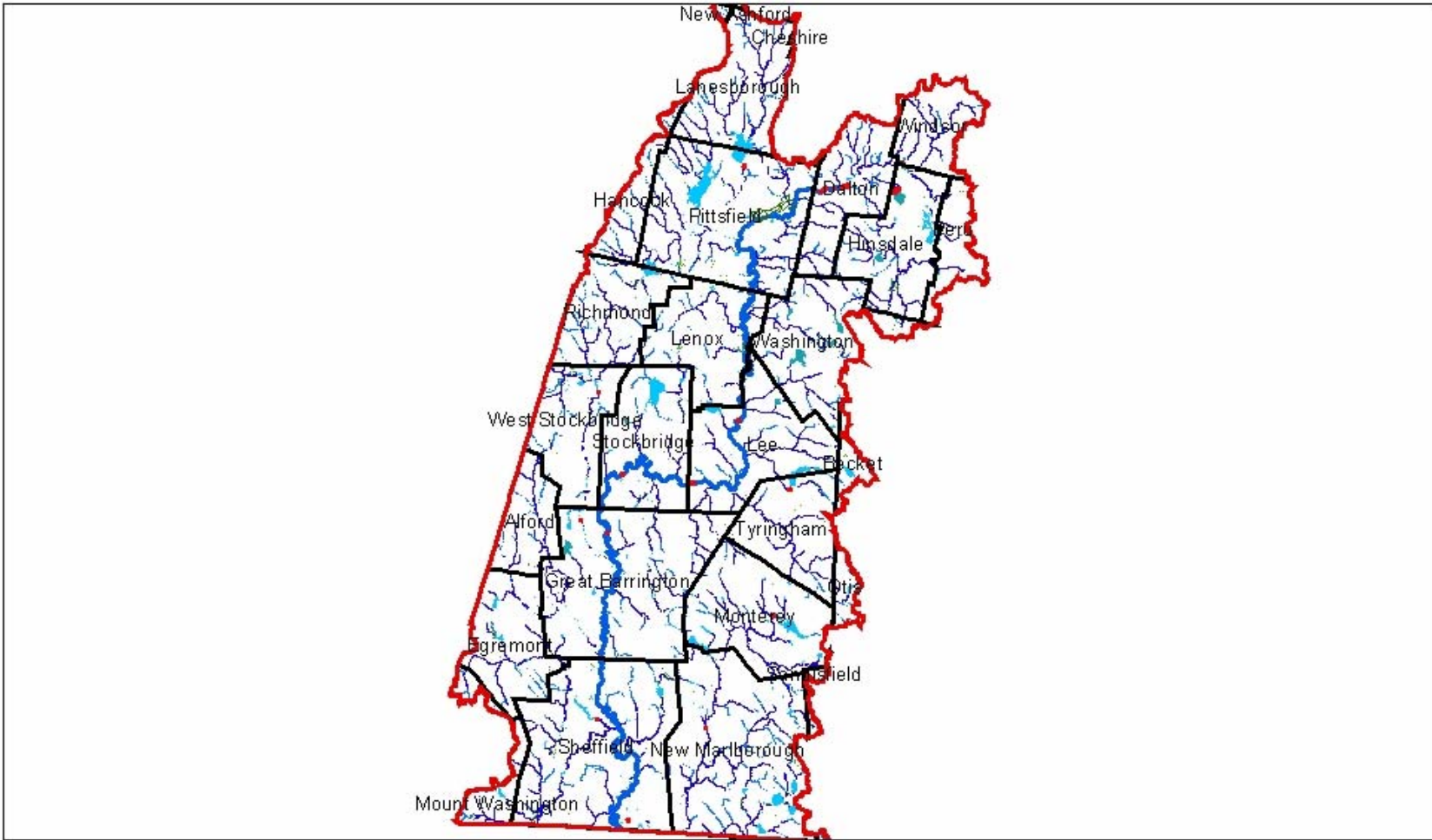
- Massachusetts_Towns
- Residential Properties Tested for PCBs
- Berkshire_County_Streets
- Rivers/Streams**
 - River/Stream
 - Intermittent Stream
- Water Bodies**
 - Flat
 - Wetland
 - River
 - Lake/Pond

Residential Properties Tested for PCBs in Pittsfield, MA








0.5 Miles

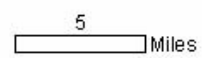
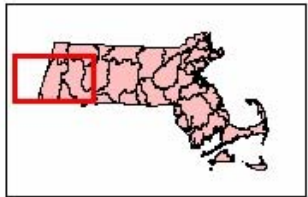
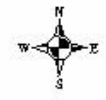




Legend

-  Housatonic River Watershed
-  Housatonic Watershed Towns
-  Former Oxbows
-  GE Sites
-  Housatonic Watershed Dams
-  H_River_Fish_Advisory_Extent
-  Public Surface Water Supply
-  Lake, Pond
-  River
-  Wetlands
-  Stream
-  Intermittent Stream

Housatonic River Watershed



Sources of Data: Children 0 to 3 Years of Age

- MA DPH Early Intervention Program
 - Serves eligible children suspected of having a developmental delay or a condition that could result in delay
 - Information available:
 - Developmental disabilities
 - Level of severity
 - ICD-9 Code & Description

Proposed Case Definition: Children 0 to 3 Years of Age

- ICD-9 Descriptions
 - Floppy Infant Syndrome/Hypotonia
 - Global developmental delays
 - Mild to severe hearing impairment
 - Hypothyroidism
 - Autism
 - Attention Deficit Hyperactivity Disorder
- Developmental Delay in one of the following domains:
 - Gross motor*
 - Fine motor*
 - Expressive language
 - Receptive language
 - Cognitive*
 - Social/emotional
 - Adaptive/self-help*

Sources of Data: Children 3 to 10 Years of Age

- MA Department of Education Individual Education Programs (IEPs)
 - Implementation due to Individuals with Disabilities Education Act Amendments of 1997
 - required the early identification and intervention of developmental disabilities through the use of community-based programs

Proposed Case Definition: Children 3 to 10 Years of Age

- Intellectual Impairment*
- Sensory/Hearing Impairment
- Communication Impairment
- Sensory/Vision Impairment
- Neurological Impairment*
- Health Impairment*
- Emotional Impairment*
- Physical Impairment
- Specific Learning Disability*
- Multiple Disabilities*
- Deaf/Blind
- Developmental Delay*
- Autism

Development of Data Sharing Agreements

- Consultation with DPH legal office
- Inter and Intra agency meetings
(identification of specific variables)
- Drafting of detailed legal agreements
(FIPA; DPH 24A process; DOE regulations)

Problem Development and Evaluation

- Early 2004 – MA DOE became aware of FERPA and MA state law likely (?) pre-empted
- 2004 – 2005 – MA DPH EI records may also be affected by FERPA

2003 Federal Guidance/FERPA

- Federal memorandum restricted historically expansive interpretation of “authorized representative” (precluding interagency data sharing agreements/MOUs)
- “Authorized representatives” must be under “direct control” (employee, contractor)
- Concern expressed that “unlimited discretion for data matching purposes violates prohibition on disclosure without authorized consent”

New DOE Conditions for Data Release

- Aggregate data only
- Entity receiving data is “authorized representative” – DPH is not –
- Project related to a study commissioned by DOE

(otherwise: get parental consent)

Arguments Put Forth (1)

- Claim that this surveillance project is a study that will benefit an educational entity
- No, just because a DPH initiated study may benefit an educational entity, this does not transform the project into one done “for or on behalf of”

Arguments Put Forth (2)

- Claim that this surveillance project “improves instruction”
- Unconvincing to DOE that this project will have a direct impact on instruction

Arguments Put Forth (3)

- Claim a public health and safety emergency
- General reaction that this only applies to narrowly defined specific situations that present imminent threat (bioterrorism attack; not traditional surveillance)

EI Data: Possible FERPA Applicability

- Are EI records “education records”? If so, FERPA may likely apply
- IDEA is the legal authorization for EI and IDEA references FERPA in certain areas
- If FERPA applies, data sharing outside of the EI program itself may be prohibited
- Waiting for further legal review

Solutions Being Explored

- Obtain parental consent
- Education agencies direct control
- Reinterpret (broaden) the law (again)
- Legislative initiatives to amend FERPA
- Outreach to stakeholders

For more specific information from the
federal DOE visit:

<http://www.ed.gov/offices/OII/fpco>