Environmental Public Health Tracking:

Assessment of Developmental Disabilities among Children in Berkshire County and Opportunities for PCB Exposure

FINAL REPORT

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Prepared by

Environmental Toxicology Program
Bureau of Environmental Health
Massachusetts Department of Public Health
250 Washington Street
Boston, Massachusetts 02108

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BACKGROUND/INTRODUCTION:

Berkshire County is located in western Massachusetts and comprises 32 cities and towns. Dalton, Lanesborough, Lee, Lenox, Pittsfield, Great Barrington, Sheffield, and Stockbridge are the eight communities of the County's Housatonic River area (HRA); an area which has experienced polychlorinated biphenyl (PCB) contamination released from a General Electric (GE) facility located in Pittsfield, Massachusetts. Between 1936 and 1976 PCBs were used by General Electric (GE) in the manufacture of electrical products and reached the Housatonic River and surrounding areas in large quantities by way of direct and indirect discharges and disposal. In 1982 the Massachusetts Department of Public Health (MDPH) environmental public health activities in the HRA began with the State's first freshwater fish consumption advisory which was based on PCB contamination in the Housatonic River. There have been many MDPH investigations and environmental regulatory agency remedial actions during the past 25 years at the GE sites and the HRA. MDPH activities have included but have not been limited to evaluations of cancer incidence in the HRA, completion of public health assessments for various GE sites in Pittsfield, a large-scale exposure assessment measuring PCBs in blood among HRA residents, several additional fish or wildlife consumption advisories, and most recently evaluating indoor environmental and health concerns at the Allendale School in Pittsfield.

Developmental disabilities among children suspected of being related to PCB exposure opportunities has been an ongoing concern among HRA residents. Toxicological studies demonstrate the effects of PCBs through disruption of the thyroid system (Brouwer et al., 1998) and epidemiological evidence suggests that exposure to PCBs can lead to delay and impairment in psychomotor and neurological development (Ribas-Fito et al., 2003; Gladen et al., 1998; Huisman et al., 1995a, 1995b; Walkowiak et al., 2001; Chen et al., 1992). Strong evidence suggests that the interaction of genetic, toxicological, and social factors is responsible for developmental disabilities such as cognitive and behavioral deficits (Schettler, 2001). Children can be exposed to PCBs either prenatally or postnatally. Prenatal exposure can occur when PCBs reach the fetus by crossing the placenta. Prenatal exposure to PCBs has been associated with deficits in cognitive development in children, especially with respect to memory (Jacobson et al., 1985). Because PCBs are lipophilic, they can become concentrated in the fat of breast

milk and postnatal exposure can occur through breastfeeding. Dose or maternal body burden and duration of breastfeeding are factors considered when estimating postnatal exposure via breastfeeding (Jacobson et al., 2001). Additional exposures to PCBs can occur through the diet from fish, meat and dairy.

Given the extent of historical PCB contamination in the HRA, linking PCB contamination data with available developmental disability data had scientific merit and hence, MDPH Bureau of Environmental Health (BEH) proposed this linkage as one of its tracking projects for the U.S. Centers for Disease Control and Prevention's (CDC) Environmental Public Health Tracking (EPHT) demonstration initiative. The overall goal of this project was to track developmental disabilities in Berkshire County for children ages 0-10 years old and link to available PCB contaminant data in order to determine whether further study or public health follow up is warranted (MDPH 2004). EPHT is aimed at: (1) determining the feasibility of conducting ongoing public health surveillance (or tracking), (2) integrating ongoing environmental hazards and exposures with data about diseases that are possibly linked to the environment, and (3) determining the feasibility of using existing datasets to accomplish these goals (CDC 2007). The following sections detail the methods used, analysis, results, lessons learned, and conclusions and recommendations of this EPHT effort.

METHODS:

1) Data Sources

Developmental Disabilities Primary Data Sources

There were two primary data sources used for obtaining developmental disabilities information related to children ages 0-10 years old in Berkshire County Massachusetts. The Early Intervention (EI) Program within the MDPH Bureau of Family and Community Health had a database of information on children between the ages of 0 and 3 years old receiving early intervention services in Massachusetts. MDPH provides funds to certified community-based programs for services to eligible children in the community. The EI Program serves children

who are suspected of having a developmental delay or have a condition that could result in delay. Records on each child were reported to the MDPH EI Program through a web based information system called Early Intervention Information Services (EIIS), which was protected by an encryption process and secured by password. The EI Program categorized individuals by way of physician diagnosis and corresponding International Classification of Diseases-Ninth Revision (ICD-9) codes. There were three EI programs that serviced all of Berkshire County; these were the Pediatric Development Center in Pittsfield, the First Steps Infant-Toddler Services for South Berkshires in Great Barrington, and the North Berkshires Early Intervention Program in North Adams. EI data were readily available for the period 05/01/1997 to 4/30/2004. The information contained in the EI database described a child's demographics, birth information, evaluation information and diagnoses, parent's demographics, birth and social environmental risk factors, and a child's developmental age and severity of delay. A summary of the data variables that were contained in this database are listed in Table 1.

The social environmental risk factors contained in the EI database provided information regarding other risk factors that can lead to developmental disabilities. There were several categories of risk factors for developmental disabilities discussed in scientific literature which included established risks (e.g., medical diagnosis such as down syndrome), biological risks (e.g., prenatal or early developmental events such as prematurity), and social environmental risk factors (e.g., limiting early life experiences such as parents with disabilities) (King et al., 1992). It is thought that a combination of these risk factors leads to the highest predictions of delayed development, although there is little agreement as to which combinations of risk factors leads to the best predictions (King et al., 1992).

The second primary data source used for this project was the Massachusetts Department of Education (MDOE) Individual Education Plan (IEP) records. IEPs were created following the stipulations of the Individuals with Disabilities Education Act Amendments of 1997 that required the early identification and intervention of developmental disabilities through the use of community-based programs. All school districts in Massachusetts are required to maintain and report data for all students enrolled. These educational records were electronically reported to the MDOE three times per year through the secured Student Information Management System

(SIMS). Once uploaded, these data were subject to a verification process and validated by the local districts. In an attempt to capture the same group of children that were contained in the MDPH EI dataset for this tracking effort, SIMS IEP records were requested for children ages 3 to 10 years old for the 2002 to 2005 school years. The information contained in the SIMS IEP database described a child's demographics, grade level, city/town of birth, city/town of residence (but not street address), income status, special education information, level of need, and nature of disabilities. A summary of the data variables that were contained in this database are also listed in Table 1.

Environmental Data Source

Environmental data (PCBs) in Berkshire County was obtained from the MDPH/BEH database. This database consists of U.S. Environmental Protection Agency (EPA) and Massachusetts Department of Environmental Protection (MDEP) air and soil sampling data collected for health assessments for the HRA in Berkshire County. Surface and subsurface soil samples, collected between 1992 to 2005 for approximately 400 households and approximately 100 schools, lots, and other properties, were compiled into an environmental sampling database by MDPH/BEH. In addition, PCB air sampling data collected from 1991 to 1992 and 1995 to 1996, from various air monitoring stations near the GE site, along the Housatonic River, as well as a background location (Berkshire Community College in northwest Pittsfield) were compiled into the MPDH/BEH database. A summary of the data variables that were contained in this database are listed in Table 2. Environmental data were geocoded and used for health assessments conducted for the HRA, as well as for this tracking effort.

In order to evaluate possible public health implications, estimates of opportunities for exposure to compounds (e.g. soil and air) were combined with what was known about the toxicity of the chemicals. The CDC's Agency for Toxic Substances and Disease Registry (ATSDR) has developed minimal risk levels (MRL) for many chemicals. An MRL is an estimate of daily human exposure to a substance that is likely to be without an appreciable risk of adverse non-cancer health effects over a specified duration of exposure (ATSDR 2005). MRLs should not be used as predictors of harmful (adverse) health effects. MRLs are derived based on

no-observed-adverse-effect levels (NOAELs) or lowest-observed-adverse-effect levels (LOAELs) from either human or animal studies. The LOAELs or NOAELs reflect the actual levels of exposure that are used in studies. To derive these levels, ATSDR also accounts for uncertainties about the toxicity of a compound by applying various margins of safety to the MRL, thereby establishing a level that is well below a level of health concern.

For PCBs, the rhesus monkey is the most sensitive animal species in terms of health effects, and studies in this species form the basis of ATSDR's screening values for PCBs. ATSDR derived a chronic (greater than one year) oral MRL of 0.00002 milligrams per kilogram per day (mg/kg/day) for chronic exposure to PCBs. The MRL was based on a LOAEL for immunological effects in female rhesus monkeys. A panel of international experts cited support for this chronic oral MRL from human studies (ATSDR 2000). ATSDR has also developed an intermediate (15-364 days) oral MRL of 0.00003 mg/kg/day. The MRL was based on a LOAEL for neurobehavioral effects in infant monkeys that were exposed to a PCB congener mix representing 80% of the congeners typically found in human breast milk (ATSDR 2000). ATSDR has not developed an MRL for inhalation because of a lack of sufficient data on which to base an MRL (ATSDR 2000). The chronic MRL has been used for evaluating human health concerns associated with opportunities for exposure to PCBs at the General Electric site in Pittsfield, regardless of duration or route of exposure. It is important to note that this is a very conservative assumption.

Based on this MRL of 0.00002 mg/kg/day, DEP developed a residential soil standard (cleanup standard) of 2 mg/kg (ppm) at which potential opportunities for exposure to PCBs approaching ATSDR's MRL may occur. The MDPH/BEH PCB soil data was categorized into the five following potential exposure zones based on the residential soil standard of 2 mg/kg and other reference levels (e.g. LOAELs and NOAELs):

1) < ND (0.5 mg/kg)
2) > ND (0.5) and < 2 mg/kg
3) > 2 and <20 mg/kg
4) >20 and <600 mg/kg

5) > 600 mg/kg

The first category encompassed properties at which average PCB levels in surface soil were essentially at non-detect (ND) and posed no potential opportunities for exposure to PCBs in soil. The second category encompassed properties at which average PCB levels in surface soil were detected but below MDEP's 2 mg/kg residential soil standard and posed potential opportunities for exposure to PCBs below the MRL. The third category encompassed properties at which average surface soil PCB levels were between 2 mg/kg and 20 mg/kg, which could pose potential opportunities for exposure to individuals who frequently used these properties that may approach the MRL. The fourth category encompassed properties with average surface soil PCB levels between 20 and 600 mg/kg, which could pose potential opportunities for exposure to PCBs ranging from approaching the MRL through approaching the LOAEL for individuals that frequently used these properties. The fifth category encompassed properties with average PCB levels in surface soil above 600 mg/kg, which posed potential opportunities for exposure above the LOAEL for individuals who frequently used these properties. It should be noted that these potential opportunities for exposure were based on worst-case scenarios (i.e. use of the property 5 days a week for 50 weeks per year, assuming all surface soil is accessible).

The PCB air data was also categorized into potential exposure zones by MDPH/BEH based on a comparison to background levels (0.0006 $\mu g/m^3$). Exposure areas were described in three categories:

1) Non-Detect
2) Background (0.0006 $\mu g/m^3$)
3) > Background (> 0.0006 $\mu g/m^3$)

Modeled air concentrations of PCBs were used in this project to estimate potential PCB exposure in addition to that already posed by residential surface soil. PCB air concentration areas were crudely modeled using the locations of air monitoring stations, seasonal wind characteristics, and the topography of the region. The majority of the PCB air samples were taken during the summer months, when PCB levels were expected to be highest.

Supplemental Data Sources

In addition to the developmental disability data from EI and IEP records, information from the MDPH Bureau of Health Information, Statistics, Research, and Evaluation [Registry of Vital Records and Statistics (RVRS)] and the MDPH/BEH Childhood Lead Poisoning Prevention Program (CLPPP) contained data on risk factors that are associated with developmental disabilities [e.g., low birth weight (from RVRS data) or elevated blood lead levels (from CLPPP data)]. These variables allowed us to consider other important risk factors (along with social environmental risk factors discussed earlier) as possible contributors to developmental disabilities, while also considering the residence of the child and potential PCB exposure. RVRS birth records reflect all births in Massachusetts and contain demographic, prenatal, and birth information on each child and were electronically available from 1969 to the present. Records obtained for this tracking project were for children born between 01/1993 and 12/2002. In addition to low birth weight as a risk factor for developmental disabilities, numerous studies have demonstrated an association between low birth weight and PCB exposure (Patandin, et al., 1998; Rylander et al., 1998; Fein et al., 1984; Heaton et al., 1995).

The CLPPP database is a statewide surveillance database that reports blood lead levels for children and universal screening has been required since 1988. In 2002 the Massachusetts regulation was amended requiring annual testing for all children up to age three and annual testing up to age four for children living in certain high-risk communities. Records obtained from the CLPPP database for this project included test results of blood lead levels from 02/1993-06/2003 for children ages 0-4 years old. Exposure to lead can cause deficits in learning, attention and IQ and may be a factor in the development of hyperactivity, impulsiveness, and aggression (Schettler, 2001). The variables contained in the RVRS and CLPPP databases are listed in Table 2.

2) Data Use Agreements

In compliance with the MDPH/BEH procedures for protection of confidentiality a § 24A data use agreement (Massachusetts General Laws pursuant to the provisions of Chapter 111,

Section § 24A) was completed and approved for the sharing of information contained in the primary and supplemental data sources for the Developmental Disabilities in Children and PCB Exposure project. A § 24A data use agreement maintains the confidentiality of information collected as part of a public health investigation and provides legal protections. Section § 24A requires that all information, records of interviews, written reports, statements, notes, memoranda, or other data procured in connection with an investigation shall be confidential and shall be used solely for the purpose of conducting this approved investigation. Section § 24A also states that no person or institution that provides such information or other data for this approved investigation shall be subject to any action for damages or other relief, and that such information or other data shall not be admissible as evidence in any action of any kind. The M.G.L.c.111, § 24A, also states that no person participating in this research project shall ever disclose or otherwise release any information or data relating to a specific individual, even after the investigation is completed.

3) Case Definition

MDPH EI Program and MDOE IEPs contained information regarding children with developmental disabilities, describing their diagnosis and disabilities, services received, and demographic information. Because the EI and IEP information was different, a case definition had to be defined using the available information for each database. The case definition was based on those outcomes recorded in each of the EI and MDOE (IEP) databases that the scientific literature suggests might be associated with PCB exposures, based on a review of the scientific literature (MDPH 2004). Hence, for the EI Program (data for children ages 0-3 years), individuals with the following diagnoses (and IDC-9 codes) met the established case definition describing developmental disabilities consistent with PCB exposure outcomes and were focused on in this tracking project:

- Floppy Infant Syndrome (781.9) and Hypotonia (728.9)
- Global developmental delays (783.4)
- Mild or moderate hearing impairment (744.00)
- Severe hearing impairment (389.9)

- Hypothyroidism (244.9)
- Congenital hypothyroidism (243)
- Attention Deficit Disorder (314.0)

Functioning level, in months, was also recorded for each child in the following seven domains: gross motor, fine motor, expressive language, receptive language, cognitive, social/emotional, and adaptive/self help. Individuals with developmental delay in the following four domains met the established case definition describing developmental disabilities consistent with PCB exposure outcomes and were focused on in this tracking project:

- Gross motor
- Fine motor
- Cognitive
- Adaptive/ Self Help

According to the EI Program, functional level was categorized in months and described by three categories of development: age appropriate/mild, moderate, and severe delay. A child was considered to meet criteria for early intervention services if they had moderate or severe developmental delay defined by the number of standard deviations below age appropriate functioning level, in one or more of the seven domains. The following table shows the category of delay in months of which a child would be described for their chronological age.

CHILDREN'S FUNCTIONAL LEVEL IN MONTHS

	Months Delayed		
Chronological Age	**Age/Mild**	**Moderate**	**Severe**
0 to 6 Months	0 - 1.0	1.5 - 2.0	2.5+
7 to 12 Months	0 - 2.5	3.0 - 4.5	5.0+
13 to 18 Months	0 - 3.5	4.0 - 7.5	8.0
19 to 24 Months	0 - 5.5	6.0 - 9.5	10.0+
25+ Months	0 - 5.5	6.0 - 12.5	13.0+

The MDOE IEP (data for students ages 3-10 years) used one of 13 categories to describe the overriding disability condition for a student receiving special education services. These categories were: intellectual, sensory/hearing, communication, sensory/vision, emotional, physical, health, specific learning disability, sensory/deaf – blindness, multiple disabilities, autism, neurological, and developmental delay. Students placed in any one of these thirteen categories were included in this tracking project, but the project focused on students in the following seven categories. The decision to focus on these categories was based upon findings in previous studies investigating possible associations between PCBs and developmental effects (e.g. Rice et al., 1999).

- Intellectual
- Neurological
- Health
- Emotional
- Specific Learning Disabilities
- Multiple Disabilities
- Developmental Delay

Linkage

Once the children for the Developmental Disabilities Databases were identified, datasets providing supplemental information such as low birth weight and blood lead levels were incorporated (e.g. CLPPP and RVRS data). Data available for children from each of the programs were matched by child's last name, first name, middle initial, date of birth, and gender. Address information from each of the linked data sources created an address history for each child that described where they lived in relation to available environmental data. MDPH/BEH evaluated data by looking at types of disabilities that were consistent with PCB exposure outcomes (established by review of scientific literature), by identifying children that had a residence where PCB soil sampling was conducted, and by considering other risk factors for developmental disabilities.

Crude Period Prevalence Maps

Crude period prevalence rates were calculated for Berkshire County to show the proportion of the population that had specific developmental disabilities over a period of time. These calculations of prevalence were called crude because the various factors that can influence these rates (e.g. household income, education, access to resources) were not controlled for in the calculations. Ninety five percent confidence intervals were also calculated to express the degree of confidence in the rate(s). The more narrow the range of upper and lower confidence intervals, the less chance of variability and the greater level of precision. Confidence intervals calculated for this project also indicated the statistical significance in the numbers compared. If the confidence intervals for two rates that were being compared in this analysis do not overlap then they are considered to be truly different from one another and are described as statistically significantly different. If the confidence intervals of two rates that were being compared overlapped, then we cannot say that the two numbers were truly different. Due to the instability of the rate, rates were not calculated for a city/town or CT if there were less than five children identified within that community.

4) FERPA Barrier

Due to reinterpretation of the Family Educational Rights and Privacy Act (FERPA) by the U.S. Department of Education (US DOE) Family Policy Compliance Office (FPCO) that was communicated during the first half of this demonstration project, MDPH/BEH was denied direct access to identifying information in the Massachusetts Department of Education (MDOE) SIMS database. In January of 2003 new federal guidance from the US DOE reinterpreted the historical expansive interpretation of "authorized representative," which completely precluded data sharing agreements between health and education agencies. Concern was expressed that "unlimited discretion for data matching purposes violates prohibition on disclosure without authorized consent." Despite MDOE regulations that provide MDPH access to school health records for purposes of public health investigations (see M.G.L 105 CMR 300.192), MDOE's interpretation of this federal policy is that their ability to release SIMS data to another entity is significantly

restricted and permitted only if (1) the data are aggregate, (2) only if the other entity is their "authorized representative", or (3) if the project is related to a study commissioned by MDOE.

With the federal restrictions on access to individual information (e.g. name) in the MDOE data, MDPH/BEH was required to develop a process to attempt to overcome this unexpected barrier. Through extensive discussion with the MDPH Office of the General Counsel and MDOE officials, a method to seek active consent from parents with children on IEPs and living in Berkshire County was developed. A new Memorandum of Agreement (MOA) between the MDPH and the MDOE was prepared to describe how the data from the MDOE SIMS database would be shared and to ensure the confidentiality of their data in compliance with the state and federal laws concerning access to and confidentiality of personally identifiable information about students and data subjects, including FERPA, 20 U.S.C. § 1232g and 34 CFR Part 99; the Massachusetts student records law, 603 CMR 23.00; the Fair Information Practices Act, M.G.L. c. 66A; and M.G.L. c. 111, § 24A. The MOA stated that upon receipt of the signed consent forms from parents or guardians, MDOE would release to the MDPH specific student identifiers and special education information on students 3-10 years old as contained in the MDOE SIMS database.

MDPH/BEH prepared consent form packets for the local school districts to distribute by mail by school officials to the parents/guardians of children receiving IEP services. Extensive communication occurred between the MDPH/BEH and the Berkshire County school districts and a total of two mailings asking for participation were conducted. Each consent packet consisted of a letter to the parent/guardian signed by the Commissioner of Public Health and the Commissioner of Education, a project information sheet, a consent form, and a return envelope. The consent form asked for the parent/guardian's signature, student name, date of birth, and current address. Of the 1,325 packets mailed to parents/guardians in Berkshire County, 44 % of the consent forms were returned and separated by the school districts into consenting (n=407) and non-consenting (n=176) groups. All student information was blinded to the MDPH/BEH staff and only the signed forms (n=407), in which the parents/guardians consented to participate, were forwarded to MDPH/BEH. Copies of the signed consent forms from the local school districts were then forwarded [along with an electronic listing of consenting student's name (last,

first, and middle), state assigned student identification (SASID) number, and date of birth] to the MDOE for request of SIMS data for the consenting students.

5) Geocoding and Address History

Geo-coding or digitizing was attempted for all records in the MDOE (for consenting children), EI, RVRS, and CLPPP datasets. An address history was created for each child comprising the addresses from the linked datasets. When the datasets were linked some addresses for each child overlapped and others represented a unique period of time. Addresses contained in the MDOE dataset were collected at the time of consent by the parent/guardian and represented the current address for the child, which may not have been consistent with the address of the child at the time IEP services were received. The MDOE SIMS database only collects city/town of residence and birth but not the specific street address. There could be one or more address for each child in the EI and CLPPP datasets which were linked to the date the evaluation or testing occurred. The RVRS dataset contained only one address per child which represented the biological mother's address at time of birth. A geographic information systems identification number (GIS ID) was assigned to each address in all datasets and represented the unique addresses per child per dataset.

6) Housatonic River Area Advisory Committee (HRAAC)

The Housatonic River Area Advisory Committee (HRAAC) was established in 1995 and comprised local residents, medical professionals, environmental professionals, elected officials, local boards of health, and others. MDPH staff have historically held meetings with committee members to report on the status of public health activities in the HRA and to discuss and get feedback. The MDPH/BEH worked with this committee on the developmental disabilities tracking project. The MDPH/BEH has presented to the HRAAC and updated them on the progress of this project at meetings beginning in October 2003 and continuing through 2007.

7) Data Verification:

Data verification was conducted for the MDPH EI records by traveling to the local EI programs in Berkshire County. Site visits were completed in November and December of 2005 for two of the three EI programs; quality control was not done for one program (The North Berkshire Early Intervention Program) because the program director was on extended leave during the time the site visits were conducted. EI program procedures for data entry and for uploading data to MDPH EIIS database were discussed with the program directors. During these site visits, a chart review was conducted, comparing information relevant to data variables in the EI electronic dataset for EPHT from a 5 percent random sampling of EI records. Each data field for the hard copy EI records were verified with the electronic database information looking for compatibility between the two sources (i.e. described as identical data, non-identical data, missing or additional data).

Site visits could not be performed for data verification of MDOE IEP records. The data sharing agreements for these records were specific to the electronic database only and the hard copy records for many of these school districts were housed at the local schools which were protected by the FERPA law and were outside the scope of our confidentiality agreements with the MDOE. However, data entry and verification procedures were discussed with a member of the MDOE staff that oversees the MDOE SIMS database.

Early Intervention Site Visits

The data collection and general program characteristics were similar between the programs that were visited. Each chart contained a variety of information regarding the child. Most charts did not contain an extensive family history unless directly relevant to the child's developmental situation. The MDPH EI Program designed forms for the data entry process; each chart contained copies of these forms. The data entry into the EIIS database was usually done by an administrative assistant at the EI program and cross training was done with other EI program staff members to ensure continuity of the operations. More information on the EIIS forms is included in appendix A.

The four EIIS data entry forms contained all the information necessary to verify data in the EIIS database. At the very least each chart should have contained the EIIS Referral and Discharge forms. There were several different versions of the EIIS forms showing that they had been updated over the years. There was no data verification process conducted at the local EI programs and their access to the EIIS database was limited to viewing only the local program's individual cases. When preparing to enter a new child into the EIIS database the local programs were unable to search the entire database for a child to see if they received services with another program and what the evaluation details were. Hard copies records provided by the referring program, physician, or parent were the only access that the EI staff had to information regarding previous EI services for the child seen at a different program.

Early Intervention Chart Review

The developmental disabilities dataset was reviewed to determine the proportion of records that each program contributed to the total EI data for Berkshire County. Using the Clinical Assessment Software Application (CASA), available on the CDC website, a random sampling was calculated to represent a 5 percent sampling of records for each of the three EI programs in the dataset (total of 106 records). In addition, a detailed review of the quality control sampling was conducted to ensure that the sample population selected represented developmental delay in domains that were focused on in this tracking project (fine motor, gross motor, cognitive, and adaptive self-help learning domains) as well as medical diagnosis. It was determined that this sample was representative of children with delay in developmental domains consistent with the case definition described. However, additional records were reviewed to look specifically at the diagnostic representation not covered by the 5 percent random sampling.

The First Steps Infant-Toddler Services for South Berkshires contributed 12.4 percent (n=263) of evaluation records to the total Developmental Disabilities Database (n=2,113). A total of 16 records were requested and 13 were reviewed (two records had been destroyed after 7 years and one record could not be found). The Pediatric Development Center contributed 56.7 percent (n=1,198) of records to the database, a total of 63 records were requested and 56 were

reviewed (the remaining seven were: (1) destroyed because records were older than 7 years, (4) destroyed due to mold and water damage, (1) unable to be found or (1) not recognized as client). The North Berkshire Early Intervention Program contributed 29.7 percent (n=629) of records to the total database, a total of 34 records were requested for review but a site visit could not be completed for this program due to extended absence of the program director.

In this data verification exercise, the data were separated into three categories of data that described the type of services that occurred and what forms were filled out: referral data, evaluation data, and discharge data. The following percentages describe data verification of the charts reviewed. For hard copy referral data 91.4 percent of data fields were found to match the electronic database, 3.7 percent of referral data fields were unmatched and 4.9 percent were unable to be verified. For the hard copy evaluation data 94.5 percent of data fields were found to match the electronic database, 3.1 percent of evaluation data fields were unmatched and 2.4 percent were unable to be verified. For the hard copy discharge data 87.8 percent of data fields were found to match the electronic database, 3.2 percent of discharge data fields were unmatched and 9.0 percent were unable to be verified.

The EI data entered at the local level was found to be accurate 92.5 percent of the time when compared to hard copy records collected at the time services were performed. Most discrepancies within the electronic database existed between programs that had seen the same child. For example different demographic information (e.g. name spelling, date of birth) may have been entered for a child making it difficult to link data and know that it was the same child with EI information from different evaluations at different programs. Possibly contributing to this discrepancy was the fact that the EI staff could not view or search the entire uploaded EIIS database to link a previously seen child, rather they entered a child new each time which may have resulted in some of the inter-program discrepancies. Resolving this data issue may increase quality of data for future research purposes.

MDOE/SIMS Data Verification Procedure

MDOE SIMS data were entered into the database via the web by the local school districts. Depending on the district, staff that entered the data were either hired specifically for that job or were an existing administrative person (they were provided with a data handbook). Hard copy records were stored at the individual schools, a central location for the district, or the district special education office. Once entered, data were uploaded into the SIMS database three times per year, October (or December), March, and on the last day of the school year. This gave a snapshot of the data at that time. Changes could be made to the uploaded data if a mistake was made (by making individual changes on line or uploading the entire dataset again); however any additional data in reference to the child's progress was entered as a new entry. The MDOE performs a system validation and cross checking process of the SIMS database: 1. System validation looks for empty fields and inappropriate codes; 2. Cross checking makes sure the individual variables match and are consistent for the child. A written description of their data verification process was not available.

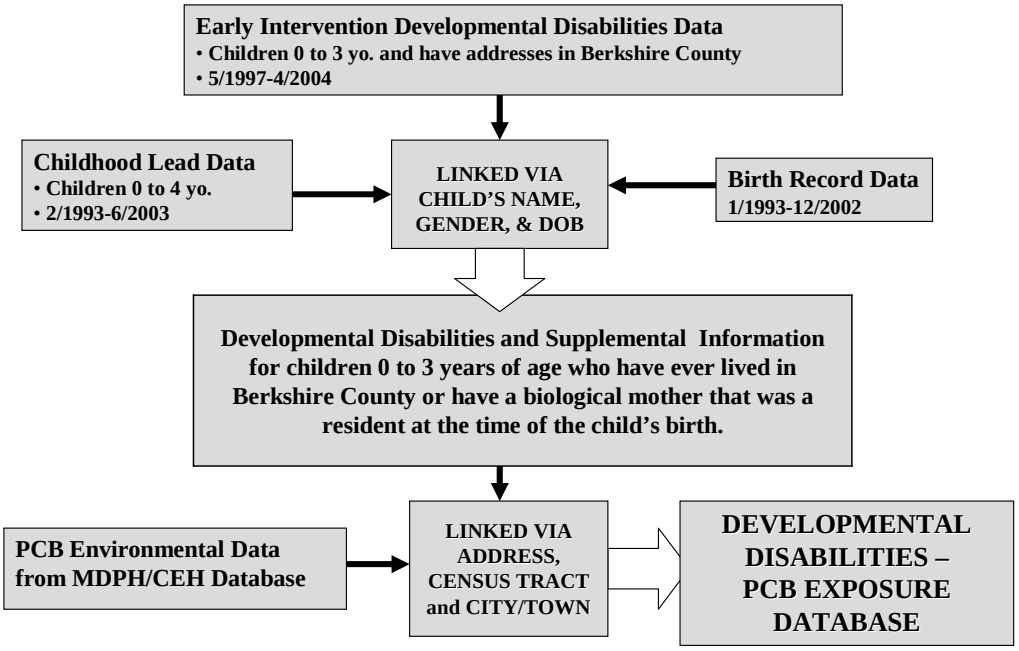
DATA ANALYSIS:

Early Intervention Data Analysis

Linkage of primary and supplemental data sources has provided a geocoded address history for each child that represents unique periods of time. To closely evaluate the residence for each EI child, in relation to opportunities for exposure to PCB's in soil and air, mapping was done using the child's address history and geographic locations of environmental sampling data. This analysis was done by looking at EI children from the case defined subgroup of developmental disabilities and excluding those children with major risk factors (see Figures 1 and 2). Children were excluded who had low birth weight (<2500g), who had blood lead levels greater than or equal to 10 μg/dL prior to their diagnosis of developmental delay, or who had one or more social environmental risk factors at some point in their early intervention services. These children were eliminated to focus on the group of children who had no readily known risk factors for developmental delay. For this analysis the CLPPP addresses were limited to

addresses for EI children prior to or equal to the date of EI evaluation in which the diagnosis of developmental delay was made. This eliminated CLPPP addresses that may have matched environmental sampling points, but would not have contributed to prior developmental disability outcomes.

Maps were then evaluated visually and using address linkage to determine if any children with developmental disabilities (and excluding other risk factors for developmental disabilities) had addresses that matched addresses for which PCB sampling data were available. Matches resulting from data linkage were then investigated to look at details of the potential PCB exposure and extent of developmental disabilities. Date of birth, diagnosis dates, remediation date for the residence, contamination levels, and air sampling boundaries from crude air modeling were analyzed for these children. The address information for each child in all three datasets was compared to the PCB sample address. The following figure illustrates this linkage.



The initial EI analysis was an effort to look at the most conservative EI group, excluding those with other non-environmental risk factors that are recognized to be associated with developmental disabilities based on a review of scientific literature. Because of the conservative

nature of this analysis, it was appropriate to look similarly at the remaining EI children who did not meet the subgroup case definition of developmental disabilities including those eliminated from the initial analysis based on additional risk factors for developmental disabilities (e.g. lead levels of concern or low birth weight). Address histories of these children were then compared to the linked PCB residential sampling address information and matches were investigated to better evaluate potential PCB exposure and extent of developmental disabilities. This second analysis was also conducted to demonstrate the capability of utilizing this linkage for surveillance and the ability to manipulate the data for a variety of analytical approaches.

Early Intervention Crude Period Prevalence per City/Town and Census Tract (CT)

Crude period prevalence rates were calculated and mapped for EI children who met the developmental disabilities case definition, excluding those with the major risk factors previously discussed. To calculate these rates each child had to be assigned only one address and then each address was assigned to a city/town and also to a census tract. The following steps were taken to better categorize the EI addresses for children with developmental disabilities and assign a single EI address per child that was consistent with the date of earliest diagnosis:

Step 1: eliminated any address that could not be geo-coded and mapped.

Step 2: eliminated duplicates of identical addresses with formatting differences.

Step 3: eliminated any address not in Berkshire County

Step 4: If greater than one address still existed per child, compared address with associated evaluation date; kept only addresses associated with the date of first diagnosis with developmental delay.

These crude period prevalence rates were calculated using 2000 census data, the most appropriate data available. Period prevalence rates were calculated using the number of EI children (meeting the case definition and without major risk factors) between 1997 and 2004 residing in Berkshire County assigned to the city/town or census tract divided by the 2000 census population of the city/town or census tract for children 0-3 years old. 95% confidence intervals were also calculated for these rates.

Department of Education IEP Analysis

Data analysis for the MDOE IEP records was limited as a result of incomplete data collection due to the FERPA barrier and poor address information available. Evaluation of residential addresses for consenting students was done using the student's current address at the time of consent for both the students meeting the developmental disabilities case definition and those that did not. Student's address histories (comprised of linked datasets) were evaluated in relation to PCB soil and air contamination data by mapping each address and comparing to the environmental sampling data. Individual students that matched an environmental sampling address were then investigated to look at details of the potential PCB exposure and extent of developmental disabilities.

MDOE IEP Crude Period Prevalence per City/Town

In order to calculate and map crude period prevalence based on complete MDOE IEP data, aggregate data describing students between the ages of 3 and 10 years old on IEPs during any of the 2002-2003, 2003-2004, 2004-2005 school years and living in Berkshire County, was requested from MDOE. MDOE data for 2002-2003 was not available and therefore period prevalence rates were calculated for the 2 year period 2003-2004 and 2004-2005. The students on IEPs were compared (by city/town of residence) to the total number of students ages 3-10 years old enrolled for any of the 2003-2004 and 2004-2005 school years and living in Berkshire County. Period prevalence rates were also calculated using aggregate data to describe those students on IEPs that met the developmental disabilities case definition compared to the total population of children on IEPs for Berkshire County. Confidence intervals were also calculated for these crude period prevalence rates.

RESULTS:

As mentioned, due to the FERPA barrier the MDOE data were compiled through an active consent process and not through analysis of the MDOE SIMS database information itself,

which would include all children in Berkshire County. Thus, the results of this tracking project are discussed separately for the EI data versus the MDOE data.

1) Early Intervention Data

Early Intervention data consisted of children who participated in the EI program between 05/01/1997-04/30/2004. Of the 2,375 children referred for services in the EI dataset for Berkshire County, there was evaluation information for 2,113 children (Figure 1). Not all children referred to the program were evaluated for EI services. Information in this dataset did not include a description of why some children referred did not receive services; some possible explanations provided by the EI programs were that the family declined services or moved before the child's first evaluation.

Of the 2,113 children evaluated, 1,305 children met the case definition for this tracking project describing developmental disabilities consistent with PCB exposure outcomes. These children are referred to as the Developmental Disabilities Subgroup in Figure 1. The Developmental Disabilities Subgroup consisted of children diagnosed with an established risk condition meeting one of eight medical diagnoses and/or children diagnosed with moderate or severe developmental delay in one or more of four developmental domains, because research has found that each has been associated with PCB exposure. The subgroup of 1,305 children was further described (Figure 1) by looking at risk factors for developmental disabilities for each EI child: birth weight, blood lead levels, and social environmental risk factors.

Birth Weight

EI birth weight data alone were not sufficient to assign birth weight to the children, given that the data were often missing. The RVRS dataset proved to be a more reliable and complete source for birth weight data. Therefore RVRS birth weight was used for each EI child, unless unavailable and in these cases the EI values were used. Of the 1,305 children (Developmental Disabilities Subgroup) evaluated, birth weight data were assigned to 97 percent of these children. Twenty four percent of these EI children (n=307) had low birth weight (<2500g).

Blood Lead Levels

Blood lead levels from the MDPH/BEH CLPPP database were linked to the EI dataset (Figure 1). Of the 1,305 EI children that met our case definition (Developmental Disabilities Subgroup), blood lead data were available for 78 percent of these children (n=1,018). Eight percent (n=102) of the EI children had blood lead levels greater than or equal to (>/=) 10 µg/dL defined by the U.S. Centers for Disease Control as a "level of concern."

Social Environmental Risk Factors

Social environmental risk factors were also described for the Developmental Disabilities Subgroup (n=1,305 children) and represented in Figure 1. The following risk factors were reported for each child in the EI dataset and referred to as social environmental risk factors in this report:

1. Children living in homes with substance abuse
2. Children living in homes with domestic violence
3. Children living in homes with multiple trauma or loss
4. Open/confirmed protective service investigation
5. Food, clothing, shelter deficiency
6. Parental chronic illness or disability
7. Child experiencing insecure attachment/interactional difficulties

Of the 1,305 children with developmental disabilities, 35 percent (n=455) had one or more social environmental risk factors in the EI dataset.

Geocoding

In order to conduct linkage analyses with PCB environmental data, MDPH/BEH's Geographic Information System staff geocoded all addresses from the health outcome data for the EI dataset, the RVRS dataset, and the CLPPP dataset. In some cases, addresses could not be geo-coded due to partial or no address information or other reasons, such as a mailing address

that did not represent the residence and could not be mapped (e.g., P.O. Box). Of the initially identified 2,375 EI children, 94 percent of the addresses were geocoded. Likewise, MDPH/BEH geocoded all the CLPPP records for children in Berkshire County during the time period of interest (15,168 records), with 84 percent of the records successfully geocoded. Finally, 96 percent of the RVRS birth records for the county were successfully geocoded. These geocoding results are represented in the following table.

	Number of Children	Number of Addresses	Number of Geocoded Addresses	Percentage Geocoded
Early Intervention Records	2,375	2,733	2,572	94%
CLPPP Records	15,168	39,056	32,776	84%
RVRS Records	13,326	13,326	12,796	96%

Linkage Analysis

Once all data from the three sources were compiled and geocoded, those EI children who met the case definition and had no project specific risk factors were identified. Of the 1,305 EI children who met the case definition and for whom EI data were available, 77 percent also had information in the RVRS database. Likewise, 78 percent of these children (n=1,305) had information in the CLPPP database. These linkage results are represented in the following table and in Figure 2.

	Early Intervention Records Linked	
	Number of Children	Percentage
EI Children Meeting Case Definition	1,305	---------
EI Children also in CLPPP	1,018	78%
EI Children also in RVRS	1,001	77%

The final group of children who met the developmental disabilities case definition and did not have any of the risk factors previously discussed, totaled 609 children. The address history for each of these children was comprised of addresses from the linked EI, RVRS, and CLPPP datasets. There could be one or more addresses for each child in the EI dataset; for the 609 children, 694 EI addresses existed and 93 percent (646 EI addresses) were mapped. The

RVRS dataset represents the biological mother's address at time of birth. Of the 609 children in this subgroup, 482 had RVRS addresses and 99 percent (475 addresses) were mapped. For analyses purposes, the CLPPP addresses were limited to addresses for EI children prior to or equal to the date of EI evaluation in which the diagnosis of developmental delay was made. For the subgroup (n=609) there were 412 CLPPP addresses and 83 percent (343 addresses) were mapped. These numbers are represented on page 2 of Figure 2.

This linkage effort demonstrated that less than one percent (n=4) of the 609 EI children had PCB soil data for their residential address (see Figures 3 and 4 for maps of residential PCB soil and air data locations). Maps have not been included to represent the children's exact addresses due to confidentiality requirements. Relevant early intervention, residential history, and risk factor information was examined for these four children to describe in more detail the potential PCB exposure scenario; this information is summarized in Table 3. In Table 3 the address information for each child in all three datasets is compared to the PCB sample address. The "Address Information" columns indicate with a check mark whether the address of the child in each dataset matches the PCB sample address. Three of the children have consistent addresses indicating that they have the same address entered into all of the databases, while one (child 2) has a change of address indicating that they did not always live at the residence where PCB soil sampling was conducted. All of the children represented in Table 3 had developmental delay in at least one of the four developmental domains and none of the children had a medical diagnosis or increased blood lead levels (reported in the database) that could be associated with their disabilities. The "PCB Environmental Data" columns describe the mean PCB soil concentrations by categories of exposure relating to DEP's residential soil standard of 2 ppm for oral chronic exposure (greater than one year), at which potential opportunities for exposure to PCBs approaching the minimal risk level (MRL) may occur. In addition exposure to PCB levels in air, determined from crude air modeling, are described as well as the time period of residential soil remediation in relation to potential exposure periods when applicable.

As summarized in Table 3, there were four children with addresses that matched a PCB residential soil sampling address. Child 2 did not live at the PCB residential sampling address until after remediation of the property occurred, crude air modeling demonstrated potential

exposure to above background levels (>0.0006μg/m^3) of PCBs in the air at this address. PCBs were non-detect in the soil at the residential address of Child 1 and potential exposure to PCB concentrations in the air above background levels (>0.0006μg/m^3) were demonstrated through crude air modeling. PCBs were non-detect in the soil at the residential address of Child 3 and PCB concentrations in the air were typical of background levels (0.0006μg/m^3). Average concentrations of PCBs were greater than 2 ppm (and less than 20ppm) in the soil at the residential address of Child 4, which is above the DEP residential soil standard and can pose potential opportunities for exposure to PCBs that may approach the minimal risk level (MRL) for chronic (greater than one year) oral exposure. There is no data for PCBs in the air for the area in which this child lived. The child's date of birth and date of diagnosis are prior to the remediation date for that property, suggesting possible residential PCB soil exposure before the property was remediated.

After completing analyses for the group of children (n=609) who met the developmental disabilities case definition and did not have any of the risk factors previously discussed, an analysis was performed to compare PCB exposure for the remaining children in the EI dataset. The address histories for these EI children (n=1,766) were examined for matches of residential address with PCB environmental data. As a result of this linkage effort there were twelve children (less than one percent) who had residential addresses that matched with PCB residential sampling addresses and PCB residential soil sampling showed similar potential exposures compared to the original group of EI children (n=4).

Early Intervention Crude Period Prevalence per City/Town and Census Tract (CT)

Crude period prevalence rates were calculated by city/town and census tract for the case defined group of EI children (n=609) previously discussed (Tables 4 and 5). Eleven EI children were eliminated from rate calculations because of addresses located outside of Berkshire County (n = 598). Crude period prevalence rates were calculated over the period of 5/1997-4/2004 and compared to 2000 census data for Berkshire County and summarized per 10,000 children. Due to the instability of the rate, rates were not calculated for a city/town or CT if the number of EI children within that community was less than five children. Figures 5 and 6 illustrate the crude

period prevalence rates across Berkshire County through colored shading and areas depicted as white represent communities where rates were not calculated.

Crude period prevalence rates by city/town in Figure 5 showed that 38 percent (n=12) of communities in Berkshire County had less than 5 children per 10,000 receiving EI services, who had a diagnosis meeting the case definition, and without any of the major risk factors. Shading patterns varied throughout the county and did not illustrate patterns consistent with information known about GE/Housatonic PCB soil contamination in the communities. The shading of the HRA also did not indicate unusual patterns of developmental effects. In addition, the two communities with the highest crude period prevalence rates were both located outside of the HRA.

The two communities that had the highest crude period prevalence were Egremont and Otis; due to the wide 95% confidence intervals for these rates it was difficult to compare them to other communities in Berkshire County and it did not appear that they were statistically significantly higher than the other communities. When comparing these towns to the crude period prevalence rates for the HRA and for Berkshire County as whole, the same conclusion was met. The two communities were not statistically significantly different when compared to the HRA or with Berkshire County because the confidence intervals overlapped. Also the HRA appeared to have a slightly lower rate compared to Berkshire County as a whole, however when comparing confidence intervals for these areas the rates were similar.

Census tract maps, as part of this analysis, provided a description of prevalence estimates within smaller geographic areas for the HRA. Figure 6 represents crude period prevalence for census tracts in Berkshire County for the same case defined group (excluding those with major risk factors) of EI children (n=598) previously discussed. Once again when examining the shading patterns throughout the county, there did not appear to be unusual patterns that could be consistent with information known about GE/Housatonic PCB soil contamination in the communities. Shading for the HRA also did not indicate unusual patterns that suggest PCB exposure opportunities were likely to have played a primary role in the occurrence of

developmental effects. It is important to note that different shading patterns could emerge if information was available regarding social and economic factors associated with these effects.

The GE site is located in CT 9012, which is considered a non-residential CT. GE is directly bordered by three CTs: 9002, 9010, and 9011 (in Pittsfield). Although recognizing the limitations of these crude maps, when examining the crude period prevalence rates in Pittsfield there did not appear to be a pattern suggesting that residential PCB contamination or exposure opportunities related to the proximity of these CTs to the GE site played a primary role in these outcomes. The two census tracts that had the highest crude period prevalence rates were 9221 (in Adams) and 9009 (in Pittsfield). When comparing the 95% confidence intervals related to these rates it was difficult to compare them to other communities in Berkshire County. Both CT 9009 and 9221 had confidence intervals that overlapped with other CT's in Berkshire County, and therefore it did not appear that they were statistically significantly higher than the other communities. Similarly, when comparing these CTs to the crude period prevalence rates for the HRA and for Berkshire County, CT 9221 did not appear to be statistically significantly different from the HRA or Berkshire County as a whole. When comparing crude period prevalence rates and 95% confidence intervals for CT 9009, it did appear that this CT was statistically significantly higher than the HRA and of Berkshire County as a whole. Also when comparing the rates for the HRA to Berkshire County as a whole, the rates appeared to be similar. The current investigation was focused on residential soil levels, however if residential proximity to the GE facility was a likely predictor in the occurrence of developmental disability outcomes then CTs 9002, 9010, and 9011 would be expected to have higher rates.

The crude nature of these rates did not allow us to control for the many social and economic factors that could impact these period prevalence rates in Berkshire County. In order to further explore CT 9009, information that was available regarding EI children and residential PCB soil data for this CT and others near GE was evaluated. From residential PCB soil sampling (compiled by MDPH/BEH for 1992 to 2005 for approximately 400 households), it could be determined that CT 9009 (in Pittsfield) had an average PCB soil concentration between 20 ppm and 600 ppm. For comparison, CT 9002 (in Pittsfield) with similar mean PCB levels was further evaluated. CT 9002 also had an average PCB soil concentration between 20 ppm

and 600 ppm and was located in closer proximity to the GE site. Crude air modeling revealed similar patterns of PCB air concentrations for these two census tracts (i.e. CT 9009 and CT 9002). However, the crude period prevalence for CT 9002 did not appear to be statistically significantly different compared to the crude period prevalence of the HRA or of Berkshire County as a whole. It is important to note that PCB concentrations in soil and air are not uniform across CTs. Census information (2000) was also evaluated for these two census tracts. By reviewing some social and economic risk factors as well as specific data such as mother's age at time of birth and residential addresses, a clear link between residential soil contamination and elevated period prevalence rates across the entire CT could not be determined from these analyses.

2) Department of Education IEP data

The consent process required extensive collaboration with MDOE (legal office and data analysts), 12 Superintendents in Berkshire County, and special education directors and staff. All correspondence with students went through the local school district point person. Efforts resulted in 11 of 12 school superintendents in Berkshire County willing to assist MDPH/BEH and participate in the consent form mailing. See appendix B for information regarding participation of districts. The non-participating district included schools in: *Alford, Egremont, Monterey, New Marlborough, and Sheffield.* Four of these towns (*Alford, Egremont, Monterey, and New Marlborough)* are outside of the HRA and do not border the Housatonic River. Sheffield is located in the southern most part of the HRA and was not known to have residential PCB contamination (based on residential soil data compiled by MDPH/BEH for 1992 to 2005 for approximately 400 households).

The MDOE SIMS dataset comprised data from two reporting periods per year (either October or December and end of school year) for the 2002-2003, 2003-2004, 2004-2005 school years, which totaled six reporting periods. The MDOE reported aggregate numbers of students from the SIMS database of 1,234 students in Berkshire County ages 3-10 years old receiving IEP services for any of the 2002-2003, 2003-2004, 2004-2005 school years. However, working with

the local school districts in conducting the active consent process, the school districts reported 1,325 children in Berkshire County ages 3-10 years old on IEPs for the same school years.

Consent packets prepared by the MDPH/BEH and mailed by the districts were sent to families of 1,325 children on IEPs. After two mailings 44 percent (n=583) of consent forms were returned either consenting or not consenting to participate. A total of 407 consent forms (176 non-consent forms) were returned from individuals consenting to participate in the EPHT effort; these participants represented 31 percent of the students receiving IEP services in 11 school districts in Berkshire County. Participation (# of consenting IEP students/# total IEP students) varied from 26 percent to 37 percent between the 11 school districts. MDOE SIMS data describing IEP services was provided for 398 of the 407 records requested from the SIMS database for this time period. Low participation precluded quantitative evaluation of data, however geocoding and linkage analysis was performed as a demonstration of the process and to assess compatibility of the MDOE dataset with other data sources in this project.

Geocoding

In order to conduct linkage analyses with PCB environmental data, MDPH/BEH's Geographic Information System staff geocoded all addresses for the 407 students in the MDOE SIMS dataset. In some cases, addresses could not be geo-coded due to partial or no address information or other reasons, such as a mailing address that does not represent the residence and could not be mapped (e.g., P.O. Box). Ninety five percent (n=388) of the 407 addresses in the MDOE SIMS dataset (consenting participants) were geocoded.

Linkage Analysis

Geocoded MDOE IEP records (of consenting participants) were then linked to EI, CLPPP, and RVRS datasets. There was linkage of 29 percent (n= 118) of the MDOE SIMS IEP student records with EI students, 79 percent (n=321) were linked with CLPPP records and 72 percent (n=295) were linked with RVRS records. Linkage results are also described in the following table.

	DOE IEP Student Records Linked*	
	Number of Students	**Percentage**
Students on DOE IEP's	407	---------
IEP Students also in EI	118	29%
IEP Students also in CLPPP	321	79%
IEP Students also in RVRS	295	72%

** Does not represent all MDOE IEP records; represents only consenting students (31%).*

Of the 398 students with IEP information, 116 met the MDOE IEP case definition consistent with developmental disability outcomes based upon the PCB literature (referred to as the MDOE IEP Subgroup). Addresses were mapped for the case defined students and compared with environmental data to determine if any of these students had addresses that matched addresses for which PCB residential sampling was available. The EI, RVRS, and CLPPP datasets contributed to some of the student's address histories. One student from the MDOE IEP subgroup (n=116) had a match to PCB soil data for one address in their residential history (see Figures 3 and 4 for maps of residential PCB soil data and air data). Information was available to describe in more detail the potential PCB exposure and extent of developmental disabilities for this student. This student had information in the EI, CLPPP and RVRS datasets; mean PCB concentration in the soil at the student's residence was found to be non-detect and there was no data for PCBs in the air in the area in which the student lived. Similarly as for the EI data analysis, MDOE IEP student addresses (n=1) from the non-subgroup of case defined students was also linked with PCB sampling data. Both the mean PCB soil and crude air modeling concentrations were below the limits of detection; the residential soil sampling showed similar potential exposures compared to the original Subgroup of MDOE IEP students.

MDOE IEP Crude Period Prevalence per City/Town

Crude Period Prevalence was calculated by city/town for the MDOE SIMS data (Tables 6 and 7). Census tract period prevalence was not calculated since only city/town (and not specific address) was available in the SIMS database. Due to the instability of the rate, rates were not calculated for a city/town if the number of IEP students within that community was less than five students. Figures 7 and 8 illustrate the crude period prevalence rates across Berkshire County through colored shading and areas depicted as white represent communities where rates were not

calculated. Calculations were done using aggregate data provided from the MDOE SIMS database to represent the total number of students on IEPs compared to the total number of students enrolled and living in Berkshire County for any of the 2003-2004 and 2004-2005 school years (as mentioned, aggregate data were incomplete and not utilized for the 2002-2003 school year). Period prevalence was also calculated using aggregate data to describe those students on IEPs that met the developmental disabilities case definition compared to the total population of children on IEPs for Berkshire County. As mentioned previously, the crude nature of these rates does not allow us to control for the many social and economic factors that can impact these period prevalence rates in Berkshire County.

Figure 7 represents crude period prevalence for cities/towns in Berkshire County for all students on IEPs between the ages of 3 and 10 years per 10,000 students. Shading patterns vary throughout the county and do not illustrate patterns consistent with information known about GE/Housatonic PCB soil contamination in the communities. The shading of the HRA also does not indicate unusual patterns that could be related to PCB contaminated areas. In addition, the communities shaded with the highest crude period prevalence category are located outside of the HRA.

Eight communities were shaded consistent with the highest crude period prevalence category; these were Adams, Becket, New Ashford, New Marlborough, Otis, Peru, Washington, and West Stockbridge. Due to the wide 95% confidence intervals for these rates it was difficult to compare them to other communities in Berkshire County; however it did not appear that they were statistically significantly higher compared to other communities. In comparing the rates for the HRA to Berkshire County as a whole the rates appeared to be similar. Of the cities/towns with the highest crude prevalence calculations, Adams had a statistically significantly higher rate than that of the HRA and of Berkshire County as a whole. Becket and Lee both had statistically significantly higher rates than that of the HRA but not of Berkshire County as a whole.

In order to further explore the prevalence in Adams we looked at information that was available regarding the residential soil data for this community and the linkage of consenting IEP student addresses. There was no known residential PCB contamination data (compiled by

MDPH/BEH for 1992 to 2005 for approximately 400 households) for Adams and there was no residential address matches for IEP students living in Adams (of the consenting participants). There were a number of factors that may have contributed to the difference seen in this community when compared to the HRA and Berkshire County as a whole.

Figure 8 represents period prevalence by city/town in Berkshire County for case defined students on IEPs compared to all IEP students. This map illustrates that 31 percent of communities in Berkshire County had less than 5 children per 10,000 receiving IEP services and also had a diagnosis meeting the case definition. Shading patterns in this MDOE map also varied throughout the county and did not illustrate patterns consistent with information known about GE/Housatonic PCB soil contamination in the communities. The shading of the HRA also did not indicate unusual patterns that suggest that PCB contamination was likely to have played a primary role in developmental disability outcomes. The communities with the highest crude period prevalence rates were Windsor and Stockbridge. The confidence intervals associated with these crude period prevalence rates for these two communities indicated that they were statistically significantly different than the majority of other communities in Berkshire County; Clarksburg, Richmond, and West Stockbridge had similar rates however. Pittsfield, Stockbridge, and Windsor had statistically significantly higher rates than that of the HRA and of Berkshire County as a whole.

To further explore the prevalence information for communities with the highest rates we compared available information regarding the residential soil data for these communities and the linkage of consenting IEP student addresses. Stockbridge and Windsor did not have any known residential PCB contamination data (compiled by MDPH/BEH for 1992 to 2005 for approximately 400 households) and had no matches of available IEP student addresses (of consenting participants). Despite the considerable amount of residential PCB soil data for the city of Pittsfield, only one IEP student address (of the case defined subgroup) matched a residential sampling address for Pittsfield. The mean PCB residential soil concentration at this address was below the level of detection and the residence was outside of the air modeling range for exposure. PCB soil sampling data for this tracking project suggests that it is unlikely to have played a primary role in this child's developmental outcome.

DISCUSSION:

Diagnosis of developmental disabilities is subjective and diagnostic criteria vary. However, although the EI and MDOE IEP data are complicated, these datasets are valuable data sources. The use of these data resources is strengthened by the linkage to other datasets that provide information on a child's residential history and risk factors for developmental disabilities. Extensive collaboration with database owners and users to understand data collection, diagnostic criteria, and evaluation processes is essential. When linking these diverse data sources it is necessary to understand the limitations of the analyses.

Address information from each of the linked data sources created a residential history for each child that described where they lived in relation to available environmental data. Residential history information was limited to the time period of the datasets and dependent on the frequency of services for the child by the various programs (e.g. MDPH EI, CLPPP). Assumptions regarding residential locations (i.e. potential exposure) were heavily dependent on the completeness of the dataset and it was not possible to confirm whether the potential exposure period for the child was captured. For example, children who moved more frequently may have had less accurate address histories represented in the developmental disabilities database. Although exposure information for this tracking project was based on conservative assumptions (e.g. MRL), the limitations for determining potential exposure opportunities should be noted. Prenatal exposure is important when exploring developmental disability outcomes and PCB exposure; however the address for the prenatal time period could not be confirmed from these tracking data sources. In addition, PCB concentrations in soil and air were the only data available for which potential exposures could be measured. Potential prenatal, breastfeeding, or dietary exposure could not be measured in this tracking effort; however these potential exposures would contribute to the overall exposure of the mother and child.

Period prevalence maps allowed for a better understanding of the residential distribution of children receiving special education services (EI and MDOE IEP) and meeting the project case definitions. Although period prevalence maps were helpful in providing a snapshot of prevalence for the time periods analyzed, they had many limitations that should be noted. A

single address for EI children had to be determined for mapping, using the address at the time of special education services to categorize the residential area (city/town or CT). Data gaps may have existed since the complete residential history of the child was not represented in these maps, the exact time period of possible exposure was unknown, and the most sensitive exposure period (i.e., prenatal exposure) may not have been represented. Supplemental information in the EI database on social environmental risk factors enabled investigators to explore potentially confounding risk factors. In addition, by linking with readily available electronic databases of children's blood lead levels and birth weight data, other potentially confounding factors were crudely controlled for in this analysis and potential patterns in relation to PCB exposures in Berkshire County were explored. Although some confounders (e.g. low birth weight and lead exposure) were crudely considered in this analysis, there were other potentially important confounders (e.g. social and economic factors) that were not able to be considered due to lack of available data for many children. These other risk factors for developmental disabilities in children could significantly impact the crude period prevalence rates across Berkshire County.

CONCLUSIONS:

This environmental public health tracking project allowed for descriptive analysis of case specific developmental disability information for children receiving early intervention services. The data sources were used to identify potential PCB exposures among children who have developmental disability outcomes consistent with PCB exposure as described in scientific literature. Other risk factors that are also associated with developmental disabilities were explored, and the potential for analysis of the impact of some of these confounders exists. Linkage, geocoding, and analysis of the developmental disabilities and supplemental databases enabled identification of some children who may have had opportunities for exposure to PCBs by way of soil and air contamination.

Less than one percent of EI addresses were able to be matched with a residential soil sampling location. One EI child of the case defined subgroup (n=609) had potential exposure to PCBs in residential soil which was above the DEP residential soil standard, and potential exposure to above background PCB air levels was identified for two of the other EI children. As

mentioned earlier in this report, due to the conservative nature of this analysis it was appropriate to look similarly at the remaining EI children (n=1,766) who did not meet the subgroup case definition of developmental disabilities including those eliminated from the initial analysis based on additional risk factors for developmental disabilities (e.g. lead levels of concern or low birth weight). Those children who had residential addresses that matched (n=12) with PCB residential sampling data showed similar exposures compared to the initial group of EI children (n=4) who also had residential addresses that matched with PCB residential sampling data. One MDOE IEP student (from those consenting to participate) of the case defined subgroup (n=116) had a matched address, however exposure for this child was deemed unlikely because residential soil sampling was non-detect for PCBs.

In general, results of linkage analyses did not reveal patterns that suggested exposure to PCBs likely played a primary role in the occurrence of developmental disability outcomes. Using the subgroup of case defined EI children compared to the population of children three years of age and under, crude period prevalence rates were calculated for cities/towns and CTs in Berkshire County. Egremont and Otis (communities not suspected of having PCB contamination related to GE) had the highest crude period prevalence rates by city/town for the subgroup (n=609) of case defined EI children (Figure 5). However, these rates had very wide 95% confidence intervals and did not appear to be statistically significantly different from other communities in Berkshire County, the HRA, or Berkshire County as a whole. The crude period prevalence rates calculated by city/town for the HRA and Berkshire County as a whole also appeared to be similar. The crude period prevalence rates calculated by census tract for the subgroup of case defined EI children were greatest for CT 9009 (in Pittsfield) and CT 9221 (in Adams) (Figure 6). These rates also had wide 95% confidence intervals that overlap with other CT rates in Berkshire County. In addition, the crude period prevalence rate calculated for CT 9221 was not statistically significantly different when compared to the HRA or Berkshire County as a whole. When comparing crude period prevalence rates and 95% confidence intervals for CT 9009, it appeared that this CT was statistically significantly higher than the HRA and Berkshire County as a whole. When this CT was further explored to see if any of the EI residential matches for PCB environmental soil sampling were located in CT 9009; there were no EI address matches in this CT from the subgroup of case defined children (n=4). While average soil

concentrations in CT 9002 (located closer to GE) were similar to CT 9009 (between 20 and 600 ppm), prevalence rates for CT 9002 were not statistically significantly different than the HRA or Berkshire County.

MDOE provided aggregate data from the SIMS database for MDPH to expand on the limited analysis resulting from low participation of MDOE IEP students. Using this aggregate data, MDPH was able to compare period prevalence for IEP students (Figure 7) and subgroups of IEP students (Figure 8) to PCB contamination throughout Berkshire County. This analysis was limited to comparisons on a town level and not by census tract. A statistically significantly higher period prevalence rate for IEP students (Figure 7) compared to all students enrolled was demonstrated for the towns of Adams, Becket, and Lee when compared to the HRA. When comparing rates to Berkshire County as a whole, Adams had a statistically significantly higher period prevalence rate. A statistically significantly higher period prevalence for the subgroup of case defined IEP students (Figure 8) compared to all IEP students enrolled was demonstrated for the communities of Pittsfield, Stockbridge, and Windsor when compared to the HRA and Berkshire County as a whole. Case specific data for the entire county was restricted by FERPA so it was not possible to evaluate important risk factor information for this portion of the analysis.

LESSONS LEARNED:

This surveillance exercise demonstrated the strengths and weaknesses of utilizing these data sources for surveillance purposes given the current interpretation of FERPA. In particular, results of this EPHT project highlighted the significant impact of the FERPA barrier in using student education records for tracking developmental disabilities in children. Due to FERPA restrictions, MDPH did not have access to the MDOE IEP database, despite the willingness in principle on the part of MDOE to share these data. Hence, in an attempt to overcome this barrier, MDOE required active consent from IEP parents, a process that typically results in low participation rates and is resource-intensive. Due to the low participation rate (i.e., 31%), it was not possible to quantitatively evaluate the MDOE IEP data for this project.

Data access, quality, and use in linkage were explored for primary, supplemental and environmental data sources in this project. Barriers to data access were significant; however this project did highlight the value of such data linkages and revealed targeted areas for improvement. Data verification efforts of EI data (comparing hard copy records with the electronic data) demonstrated accuracy with at least ninety percent of variables correctly recorded in the database. Although data verification of hard copy records was not possible for MDOE IEP SIMS records, a verification of existing system validation and cross checking processes was obtained. The quality of data in existing databases used for environmental tracking projects can vary widely depending on the applicability of the database to the tracking topic as well as the established purpose of the data collection. Although data availability was limited to dates in which electronic databases were established, overlapping information in linked data sources filled in some of the gaps of information due to missing years of electronic data.

There were a number of areas that would be helpful to address in future tracking efforts should the FERPA barrier be overcome through a change in federal policy or otherwise: The current MDOE SIMS electronic database only contained city/town level data for each child in the IEP system. In order to link with environmental contamination data, address level data would be necessary. Future use of the MDOE SIMS database could be enhanced if address information was routinely collected from here forward, if not historically. Additionally, in conducting the active consent process for MDOE SIMS records discrepancies in IEP numbers were discovered; the numbers of children on IEPs reported in the MDOE SIMS database differed from the numbers reported by the districts. Some of the differences could not be reconciled; numbers were dependent on the accuracy of reporting by districts and changes in services throughout the school year. However, it is unknown whether this affected the quality of the data and true representation of the student population.

Further, if the FERPA barrier is overcome, in future tracking efforts it would also be useful to address issues related to other tracking data sources. The current EI database does not have the ability for individual EI program staff to search for a child's records across programs. Having this ability would link the individual children who have been seen by more than one

program to a central identification which could limit some of the data errors that were discovered in the data verification process. Many discrepancies in the EI data are due to differences in the data entered by different programs and a unique identifier for the EI database may help to address this. In general, cleaning diverse databases for linkage (by name, DOB, gender, and address) in tracking efforts is labor intensive. Software that can perform linkage by incorporating a percentage of compatibility between compared records may be useful for future tracking efforts.

In the future, health data will need more simplified categories for linkage and for sharing of de-identified tracking information. For data to be used in a data sharing warehouse it would have to be categorized in a way to minimize the loss of understanding and context regarding intent, purpose, or method of original data collection. As demonstrated by this tracking project, FERPA is a major barrier in moving forward with tracking developmental disabilities and many other health outcomes that require the use of MDOE data. Until the FERPA barrier is overcome, it is not feasible to use MDOE data for tracking developmental disabilities and/or other outcomes. Recently, EI data has also been thought by some legal opinion to be subject to FERPA as well. It is unlikely that obtaining EI data through an active consent process would be more successful than the MDOE process if this was found to be necessary. However, these developmental disabilities data sources are valuable for gaining a better understanding of potential environmental exposures and related outcomes.

RECOMMENDATIONS:

Future surveillance of developmental disability outcomes can only be meaningfully conducted with modification to FERPA. If modifications are made, and with adequate funding, the MDPH can more comprehensively evaluate the role of environmental exposures on developmental disability outcomes in Berkshire County and elsewhere in Massachusetts.

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FIGURE 1: **Developmental Disabilities Tracking Project**
Population Description: Early Intervention Dataset

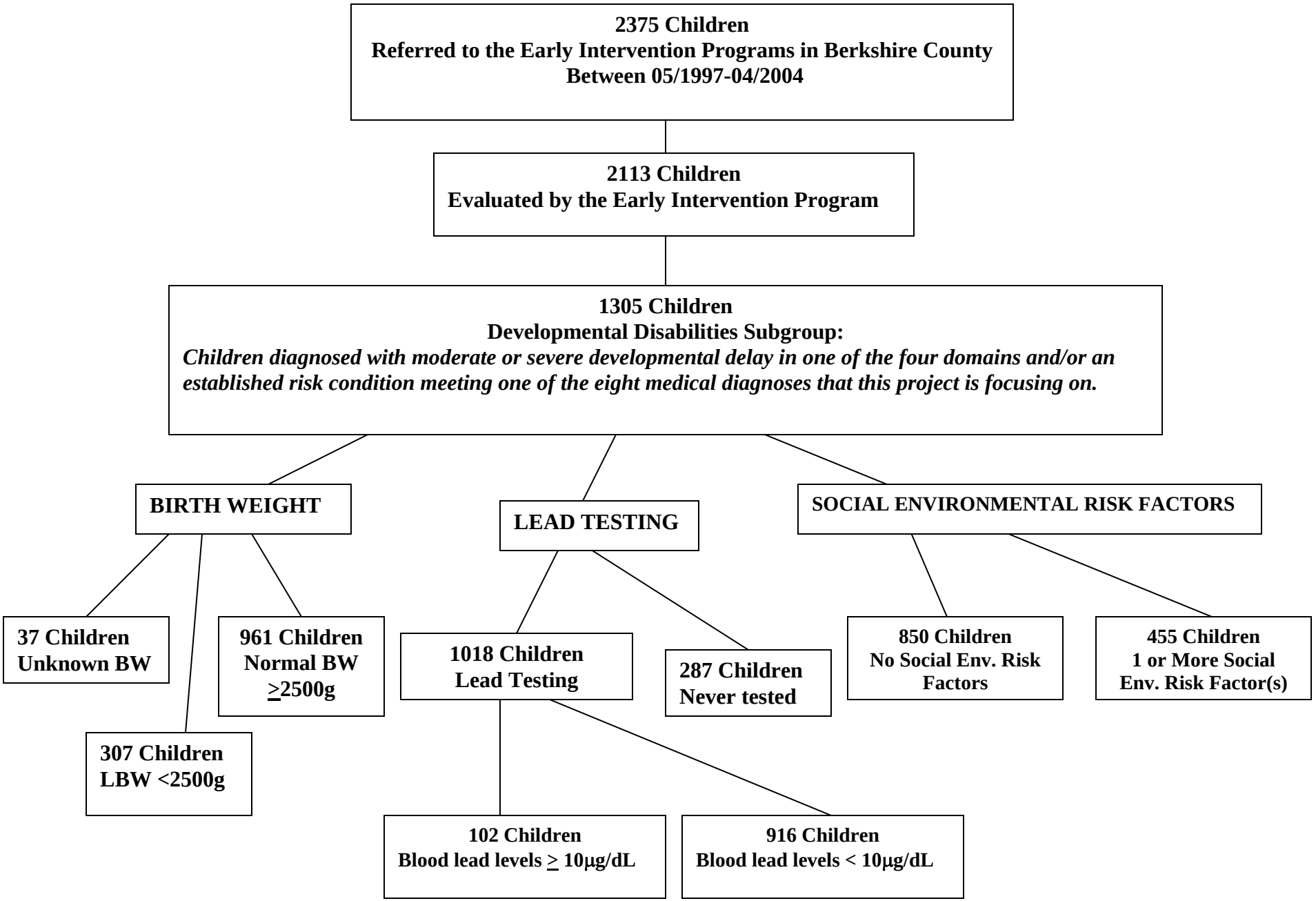


FIGURE 2:

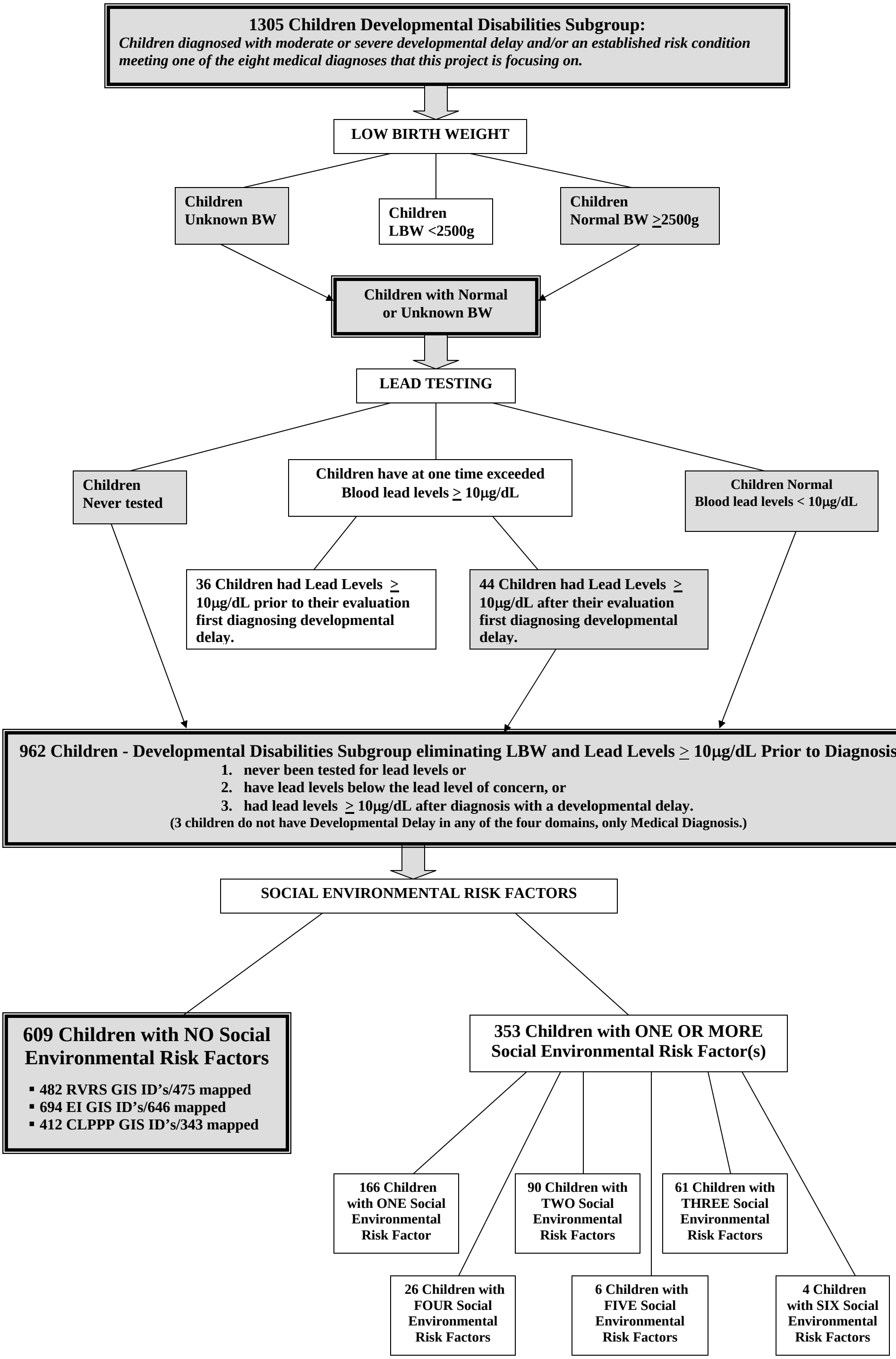
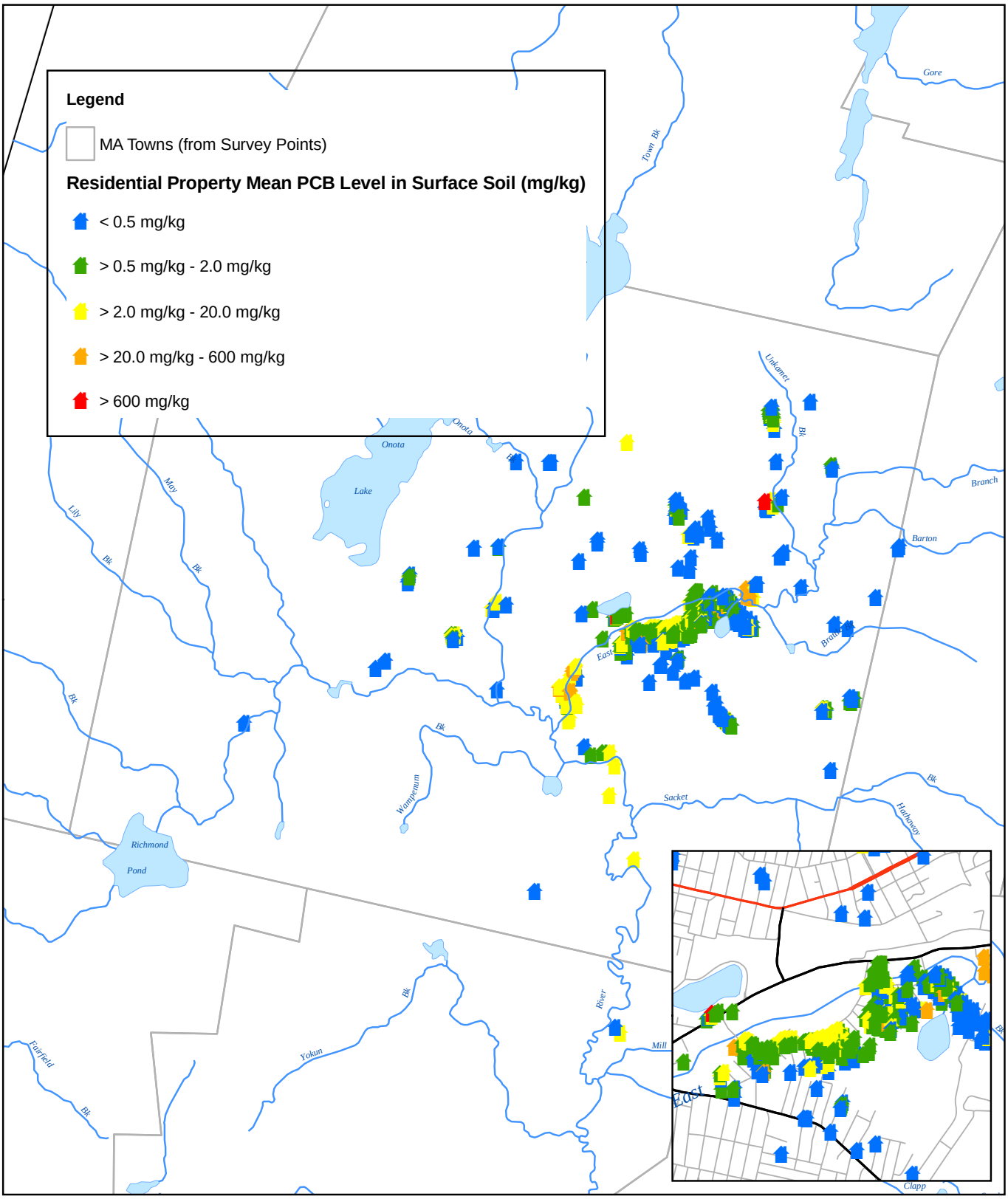

1305 Children Developmental Disabilities Subgroup:
Children diagnosed with moderate or severe developmental delay and/or an established risk condition meeting one of the eight medical diagnoses that this project is focusing on.
LOW BIRTH WEIGHT
Children Unknown BW
Children LBW <2500g
Children Normal BW ≥2500g
Children with Normal or Unknown BW
LEAD TESTING
Children Never tested
Children have at one time exceeded Blood lead levels ≥ 10µg/dL
Children Normal Blood lead levels < 10µg/dL
36 Children had Lead Levels ≥ 10µg/dL prior to their evaluation first diagnosing developmental delay.
44 Children had Lead Levels ≥ 10µg/dL after their evaluation first diagnosing developmental delay.
962 Children - Developmental Disabilities Subgroup eliminating LBW and Lead Levels ≥ 10µg/dL Prior to Diagnosis
1. never been tested for lead levels or
2. have lead levels below the lead level of concern, or
3. had lead levels ≥ 10µg/dL after diagnosis with a developmental delay.
(3 children do not have Developmental Delay in any of the four domains, only Medical Diagnosis.)
SOCIAL ENVIRONMENTAL RISK FACTORS
609 Children with NO Social Environmental Risk Factors
482 RVRS GIS ID's/475 mapped
694 EI GIS ID's/646 mapped
412 CLPPP GIS ID's/343 mapped
353 Children with ONE OR MORE Social Environmental Risk Factor(s)
166 Children with ONE Social Environmental Risk Factor
90 Children with TWO Social Environmental Risk Factors
61 Children with THREE Social Environmental Risk Factors
26 Children with FOUR Social Environmental Risk Factors
6 Children with FIVE Social Environmental Risk Factors
4 Children with SIX Social Environmental Risk Factors

Figure 3
Residential Property PCB Levels in Pittsfield, Berkshire County, Massachusetts



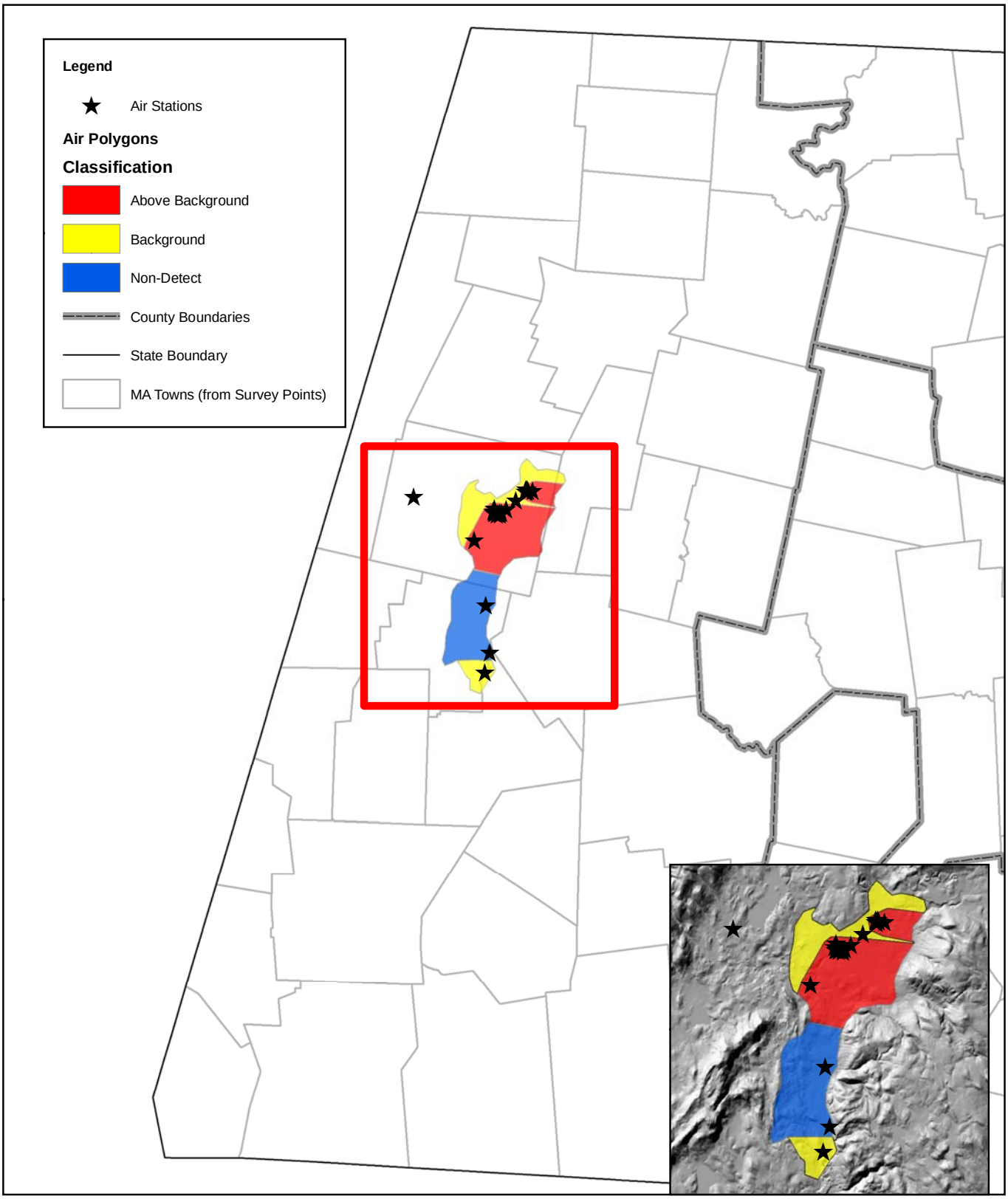
Bureau of BEH Environmental Health

Geographic data supplied by:
Massachusetts Executive Office of Environmental Affairs, MassGIS;
Geographic Data Technology, Inc.; U.S. Bureau of the Census.

0 0.5 1 2 Miles

Coordinate System: Massachusetts Mainland
State Plane Meters (NAD83)

Figure 4
PCB Air Levels as compared to background of 0.0006 ug/m3 Berkshire County, Massachusetts



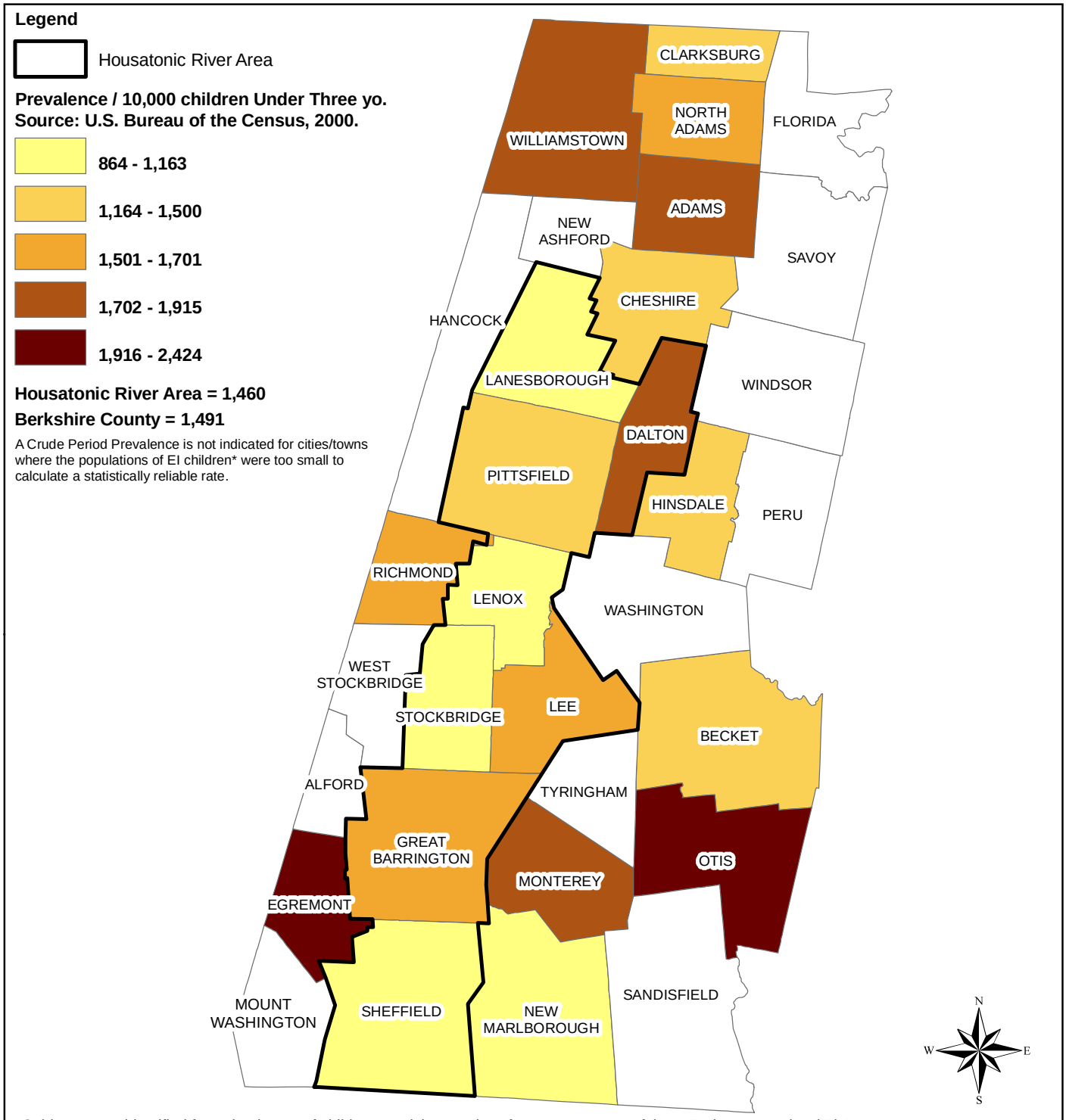
Bureau of BEH Environmental Health

Geographic data supplied by:
Massachusetts Executive Office of Environmental Affairs, MassGIS;
Geographic Data Technology, Inc.; U.S. Bureau of the Census.

0 2.5 5 10 Miles

Coordinate System: Massachusetts Mainland
State Plane Meters (NAD83)

Figure 5
Crude Period Prevalence by City/Town in Berkshire County, MA
for Children* Receiving Early Intervention Services (ages 0-3yo)



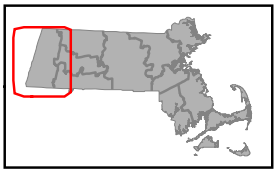
*Subjects were identified from databases of children receiving services from one or more of three Early Intervention (EI) Programs in Berkshire County, MA between 1997 and 2004 and meeting the developmental disabilties case definition, excluding those with three risk factors**.

** Risk factors include: Low weight at birth (Less than 2500g, Registry of Vital Records and Statistics); High blood lead level (Greater than or equal to 10mcg/dL, Center for Disease Control, MDPH CLPPP); One or more social environmental risk factors (1. Children living in homes with substance abuse 2. Children living in homes with domestic violence 3. Children living in homes with multiple trauma or loss 4. Open/confirmed protective service investigation 5. Food, clothing, shelter deficiency 6. Parental chronic illness or disability 7. Child experiences insecure attachment/interactional difficulties, Early Intervention Services July 2003).

Bureau of BEH Environmental Health

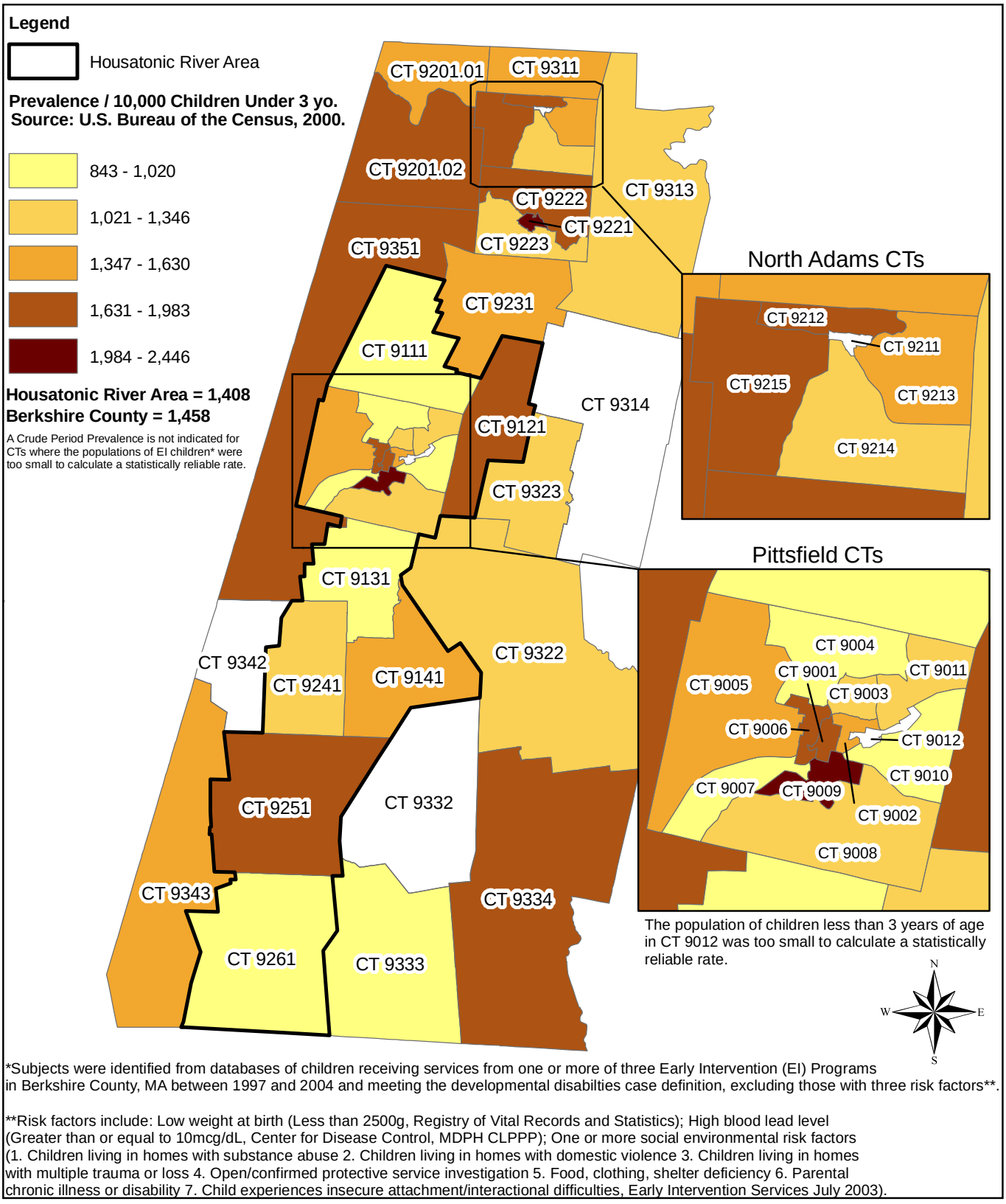
0 3.5 7 14 Miles

Coordinate System: Massachusetts Mainland State Plane Meters (NAD83)



Geographic data supplied by:
Massachusetts Executive Office of Environmental Affairs, MassGIS

Figure 6
Crude Period Prevalence by Census Tracts (CT) in Berkshire County for Children* Receiving Early Intervention (ages 0-3 yo.)



*Subjects were identified from databases of children receiving services from one or more of three Early Intervention (EI) Programs in Berkshire County, MA between 1997 and 2004 and meeting the developmental disabilties case definition, excluding those with three risk factors**.

**Risk factors include: Low weight at birth (Less than 2500g, Registry of Vital Records and Statistics); High blood lead level (Greater than or equal to 10mcg/dL, Center for Disease Control, MDPH CLPPP); One or more social environmental risk factors (1. Children living in homes with substance abuse 2. Children living in homes with domestic violence 3. Children living in homes with multiple trauma or loss 4. Open/confirmed protective service investigation 5. Food, clothing, shelter deficiency 6. Parental chronic illness or disability 7. Child experiences insecure attachment/interactional difficulties, Early Intervention Services July 2003).

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Geographic data supplied by:
Massachusetts Executive Office of Environmental Affairs, MassGIS

0 3.5 7 14 Miles

Coordinate System: Massachusetts Mainland State Plane Meters (NAD83)

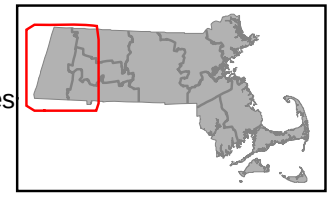
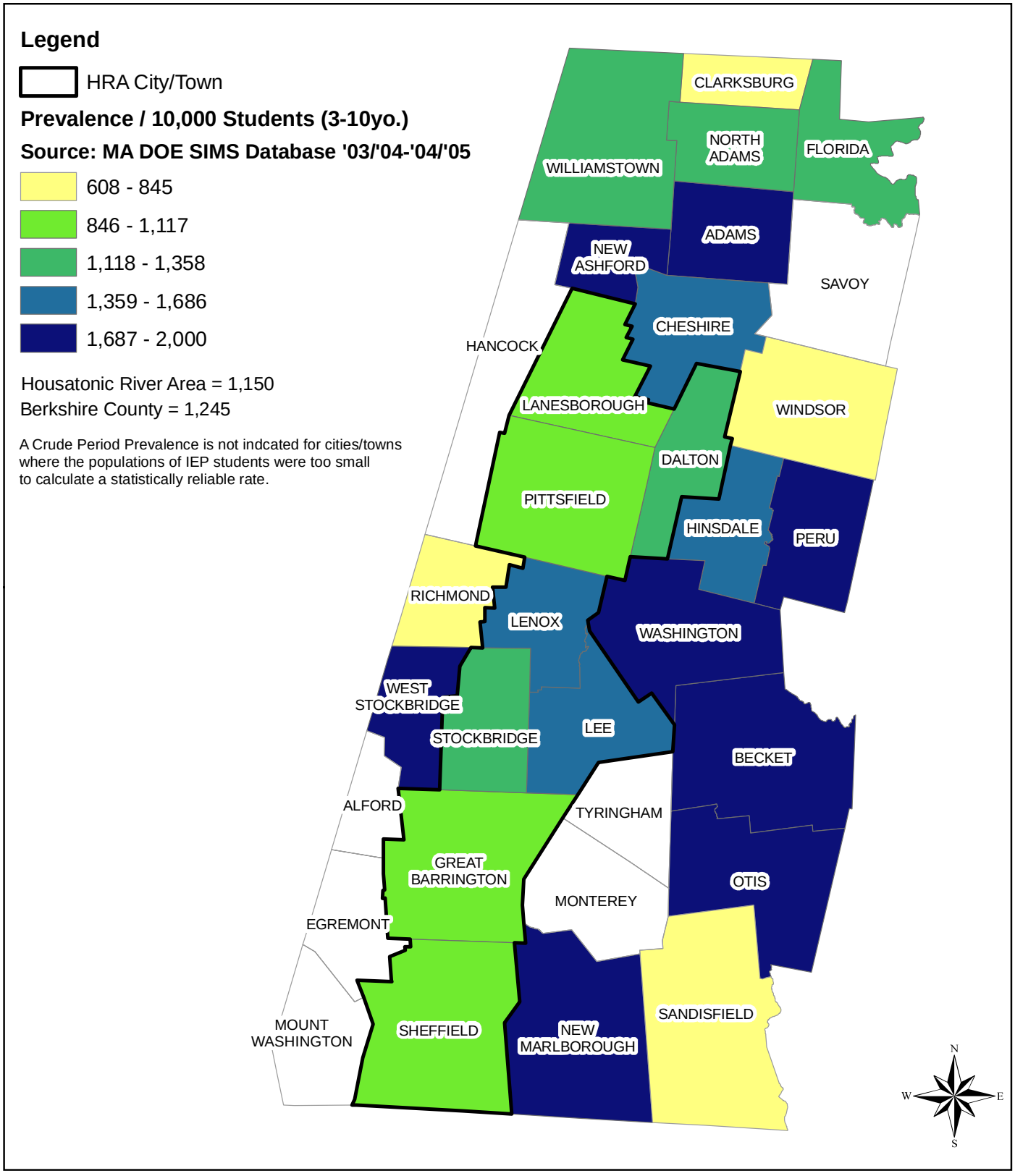


Figure 7
Crude Period Prevalence by City/Town in Berkshire County, MA
for Students Receiving IEP Services (ages 3-10yo)



Bureau of BEH Environmental Health

Geographic data supplied by:
Massachusetts Executive Office of Environmental Affairs, MassGIS.

0 2.5 5 10 Miles

Coordinate System: Massachusetts Mainland
State Plane Meters (NAD83)

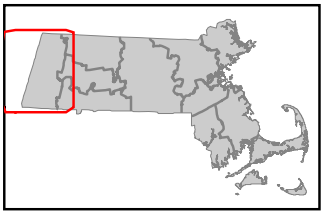
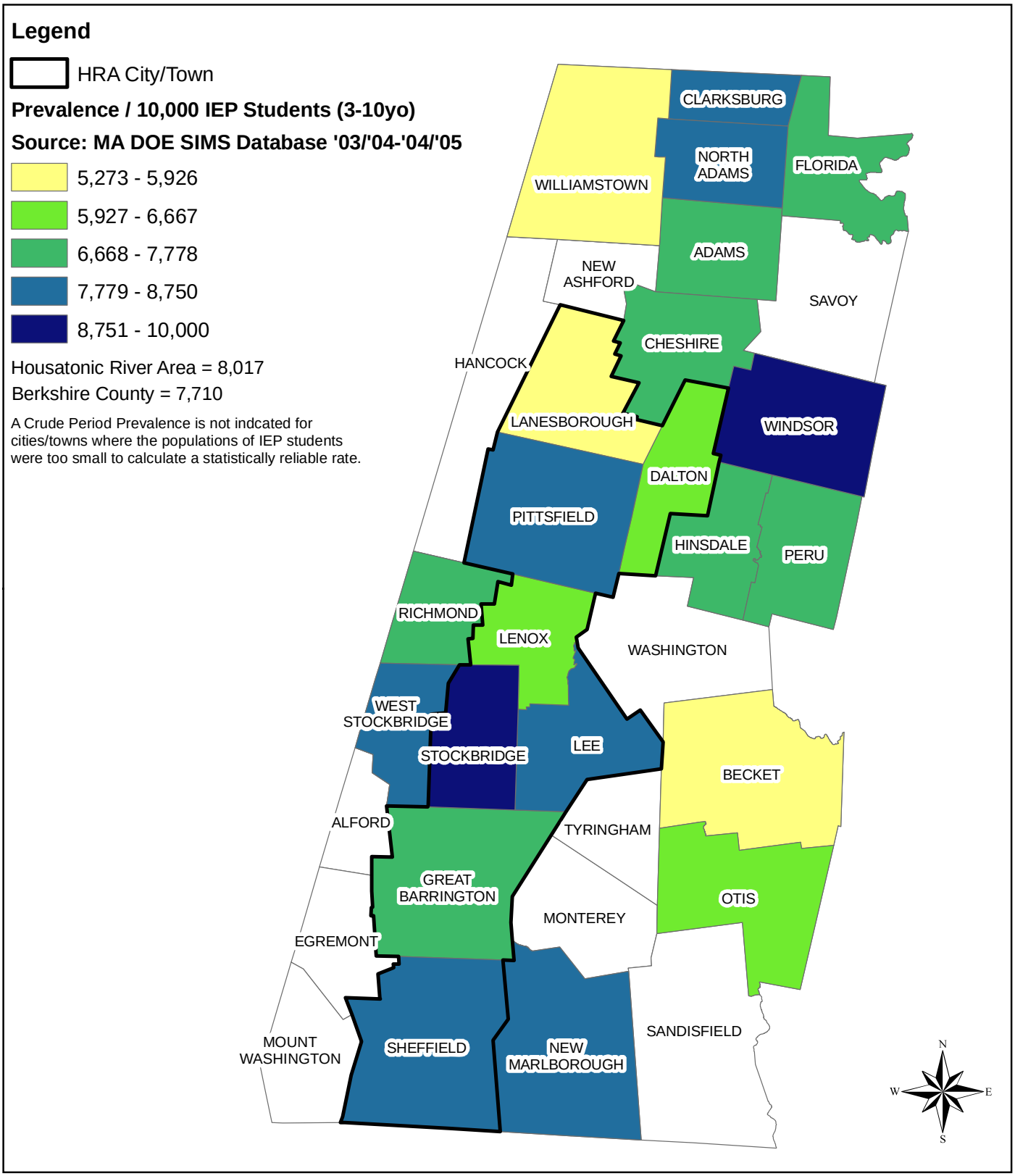


Figure 8
Crude Period Prevalence by City/Town in Berkshire County, MA
for Case Defined Students Receiving IEP Services (ages 3-10yo)



Bureau of BEH Environmental Health

Geographic data supplied by:
Massachusetts Executive Office of Environmental Affairs, MassGIS.

0 2.5 5 10 Miles

Coordinate System: Massachusetts Mainland
State Plane Meters (NAD83)

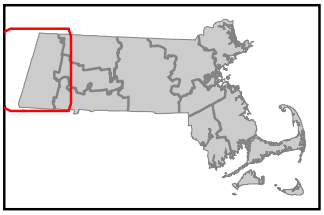


TABLE 1 - Primary Data Sources: Developmental Disabilities

Department of Education (DOE IEP) Variables

- Child's Name
- Child's Address
- Child's Date of Birth
- Date of Birth Format
- Child's Gender
- Child's Town of Residence
- SASID
- School Code
- Child's Race
- Low Income Status
- Grade Level
- Child's Town of Birth
- Special Education Elements:
  - Private Placement
  - SPED Placement Information
  - Nature of Primary Disability
  - Nature of Services
  - Level of Need
  - IEP Goals-Reason for Exiting from Special Education
  - Reason for Leaving School District
  - Evaluation Date

Early Intervention (EI) Variables

- Child's Name
- Child's Address
- Child's Gender
- Child's DOB
- Child's Gestational Age
- Birth Weight
- Child's Developmental Age:
  - Gross Motor
  - Fine Motor
  - Expressive Language
  - Receptive Language
  - Cognitive Development
  - Social/ Emotional Development
  - Adaptive/Self-Help Development
- Level of Severity:
  - Gross Motor
  - Fine Motor
  - Expressive Language
  - Receptive Language
  - Cognitive Development
  - Social/ Emotional Development
  - Adaptive/Self-Help Development
- Evaluation Tool Used
- Evaluation Date
- Diagnosis ID
- Attachment/Interactions Status
- Parental Chronic Illness or Disability
- Food, Clothing, or Shelter Deficiency
- Open/Confirmed Protective Service Investigation
- Substance Abuse at Home
- Multiple Trauma/Losses
- Domestic violence in Home
- Annual Gross Income (>7/2003)
- Income Reporting Date
- SGA/IUGR Status
- Mother's Education
- Mother's Age at Child Birth
- Father's Education

TABLE 2 - Supplemental Data Sources: Other Risk Factors

<table>
<tr><td colspan="2">Registry of Vital Records and Statistics (RVRS) Variables

Child’s Name
Child’s DOB
Child’s Sex
Child’s Birth Weight (grams)
Child’s Gestational Age
Plurality
Birth Order
Mother’s Address
Mother’s DOB
Mother’s Race
Mother’s Ethnicity
Mother’s Education
Mother’s Diploma Status
Mother’s Degree Status
Mother’s Marital Status
Mother’s Occupation
Mother’s Industry
Breastfeeding Status
Alcohol Usage (1987 – 1995)
Tobacco Usage
Risk Factors for Pregnancy
Month Prenatal Care Began
Number of Prenatal Visits
Complications of Labor and Delivery
Congenital Anomalies
Abnormal Conditions of Newborn
Neonatal Procedures
Father’s Race
Father’s Ethnicity
Father’s Education
Father’s Diploma Status
Father’s Degree Status
Father’s Occupation
Father’s Industry</td></tr>
<tr><td>Childhood Lead Poisoning Prevention Program (CLPPP) Variables

Child’s Name
Child’s DOB
Child’s Gender
Child’s Address
Date Child Tested
Sample Type
Child’s Lead Level
Lead ID</td><td>PCB Environmental Data Variables

Parcel
Address (geo-coded)
Remediation Level
Date
Air Data:
Minimum
Maximum
Mean
Residential Soil Data:
Minimum
Maximum
Mean
Median</td></tr>
</table>

TABLE 3: Early Intervention Children* with Addresses Matching a Residential PCB Soil Sampling Location.

Case Defined Subgroup* of Children Receiving EI Services (n=609)						
Child #	**ADDRESS INFORMATION** ✓ Indicates that the PCB soil sampling address matches a child's residential address for the dataset indicated.			**PCB ENVIRONMENTAL DATA (ppm)**		
	NAME OF DATASET			**Mean Soil Category[1]**	**Soil Remediation Status**	**Air PCB Level[2]**
	EI Address (MDPH EIP)	**Birth Address (RVRS)**	**Lead Address (CLPPP)**			
1	✓	✓	✓	ND	No Remediation	Above Background
2	✓	X	X	>ND <2.0[3]	Remediation Date is Pre-Exposure Period[+]	Above Background
3	✓	✓	NA	ND	No Remediation	Background
4	✓	✓	✓	>2.0[3] <20	Remediation Date is Post-Exposure Period[++]	Out of Area

ND = Non-Detect
NA = Testing not available and therefore address is not available.
X = Indicates that the child's address for that data source does not match with a residential PCB soil sampling location.

1. Typically PCB detection limits in soil are between 0.01-0.5 ppm (mg/kg). In calculating the mean PCB concentration ½ of the detection limit for the sample is used.

2. Air Background Level are =0.0006 $\mu g/m^3$

3. 2 mg/kg is MA DEP's residential soil standard, which poses potential opportunities for exposure to PCBs below the MRL (minimal risk level). The MRL is an ATSDR estimates of daily human exposure to a hazardous substance at or below which that substance is unlikely to pose a measurable risk of harmful (adverse), non-cancerous effects.

* Case Defined Subgroup = Early intervention children meeting the developmental disabilities case definition and excluding those with three major risk factors for developmental disabilities (i.e. low birth weight, lead levels >/= 10μg/dL, and/or one or more social environmental risk factors).

[+] Remediation Date is Pre-Exposure Period = Means that the date of property soil remediation is prior to the child residing at that address and exposure to the PCB soil levels recorded is unlikely.
[++] Remediation Date is Post-Exposure Period: Means that the date of property soil remediation is after the child began residing at that address and potential exposure to PCBs at soil levels recorded is possible.

TABLE 4: Period Prevalence Rate Calculations for Children* Receiving Early Intervention Services (ages 0-3 years old) by City/Town

BERKSHIRE COUNTY CITIES/TOWNS	Prevalence	Prevalence per10,000	Lower CI_ per10,000	Upper CI_ per10,000
ADAMS	0.1787	1787	1324	2250
ALFORD	NC	NC	NC	NC
BECKET	0.1429	1429	512	2345
CHESHIRE	0.1429	1429	736	2121
CLARKSBURG	0.1500	1500	393	2607
DALTON	0.1805	1805	1278	2331
EGREMONT	0.2174	2174	488	3860
FLORIDA	NC	NC	NC	NC
GREAT BARRINGTON	0.1701	1701	1172	2230
HANCOCK	NC	NC	NC	NC
HINSDALE	0.1429	1429	564	2293
LANESBOROUGH	0.0864	864	252	1476
LEE	0.1579	1579	1032	2125
LENOX	0.0891	891	335	1447
MONTEREY	0.1739	1739	190	3288
MOUNT WASHINGTON	NC	NC	NC	NC
NEW ASHFORD	NC	NC	NC	NC
NEW MARLBOROUGH	0.0909	909	149	1669
NORTH ADAMS	0.1625	1625	1295	1955
OTIS	0.2424	2424	962	3886
PERU	NC	NC	NC	NC
PITTSFIELD	0.1475	1475	1300	1650
RICHMOND	0.1622	1622	434	2809
SANDISFIELD	NC	NC	NC	NC
SAVOY	NC	NC	NC	NC
SHEFFIELD	0.1020	1020	421	1620
STOCKBRIDGE	0.1163	1163	205	2121
TYRINGHAM	NC	NC	NC	NC
WASHINGTON	NC	NC	NC	NC
WEST STOCKBRIDGE	NC	NC	NC	NC
WILLIAMSTOWN	0.1915	1915	1265	2564
WINDSOR	NC	NC	NC	NC
Berkshire County	0.1491	1491	1380	1601
Housatonic River Area	0.1460	1460	1321	1599

NC = Not Calculated. Prevalence is not calculated where the numerator is less than 5, due to instability of the rate.

CI = 95% Confidence Interval

Bolded cities/towns = cities/towns located in the Housatonic River Area

11 cases were not assigned to a Census tract (CT) because the EI address fell outside of Berkshire County.

Period Prevalence Rate Calculation: Subgroup of EI Children / Total Population (ages 0-3 years old)

* Children = Subgroup of EI Children (n=609)

TABLE 5: Period Prevalence Rate Calculations for Children* Receiving Early Intervention Services (ages 0-3 years old) by Cenus Tract

BERKSHIRE COUNTY CENSUS TRACTS	**Prevalence**	**Prevalence per10,000**	**Lower CI_ per10,000**	**Upper CI_ per10,000**
900100	0.1752	1752	1115	2388
900200	0.1498	1498	1011	1984
900300	0.1122	1122	497	1747
900400	0.0978	978	590	1366
900500	0.1605	1605	806	2404
900600	0.1983	1983	1257	2708
900700	0.0945	945	436	1454
900800	0.1319	1319	767	1872
900900	0.2446	2446	1825	3067
901000	0.0843	843	421	1266
901100	0.1277	1277	602	1951
901200**	NC	NC	NC	NC
911100	0.0864	864	252	1476
912100	0.1805	1805	1278	2331
913100	0.0891	891	335	1447
914100	0.1579	1579	1032	2125
920101	0.1630	1630	876	2385
920102	0.1837	1837	753	2921
921100	NC	NC	NC	NC
921200	0.1933	1933	1223	2642
921300	0.1463	1463	922	2004
921400	0.1346	1346	418	2274
921500	0.1667	1667	1016	2317
922100	0.2262	2262	1367	3157
922200	0.1698	1698	983	2413
922300	0.1096	1096	379	1812
923100	0.1429	1429	736	2121
924100	0.1163	1163	205	2121
925100	0.1701	1701	1172	2230
926100	0.1020	1020	421	1620
931100	0.1500	1500	393	2607
931300	0.1316	1316	241	2391
931400	NC	NC	NC	NC
932200	0.1233	1233	479	1987
932300	0.1270	1270	448	2092
933200	NC	NC	NC	NC
933300	0.0909	909	149	1669
933400	0.1724	1724	752	2696
934200	NC	NC	NC	NC
934300	0.1622	1622	434	2809
935100	0.1667	1667	806	2528
Berkshire County	0.1458	1458	1349	1568
Housatonic River Area	0.1408	1408	1272	1543

**Non-residential census tract

23 cases were not assigned to a Census tract (CT) because the EI address either fell outside of Berkshire County or, in the case of an unmapped addresss, there was more than one CT per town.

NC = Not Calculated. Prevalence is not calculated where the numerator is less than 5, due to instability of the rate.

CI = 95% Confidence Interval

Bolded Census Tracts= cities/towns located in the Housatonic River Area

Period Prevalence Rate Calculation: Subgroup of EI Children / Total Population (ages 0-3 years old)

* Children = Subgroup of EI Children (n=609)

TABLE 6: Period Prevalence Rate Calculations for DOE IEP Students (ages 3-10 years old)

Berkshire County cities/towns	Prevalence	Prevalence per 10,000	Lower CI per 10,000	Upper CI per 10,000
Adams	0.1845	1845	1554	2136
Alford	NC	NC	NC	NC
Becket	0.1921	1921	1292	2549
Cheshire	0.1472	1472	1045	1898
Clarksburg	0.0784	784	358	1210
Dalton	0.1313	1313	1036	1591
Egremont	NC	NC	NC	NC
Florida	0.1333	1333	564	2103
Great Barrington	0.1117	1117	806	1428
Hancock	NC	NC	NC	NC
Hinsdale	0.1634	1634	1048	2220
Lanesborough	0.1042	1042	670	1415
Lee	0.1686	1686	1293	2078
Lenox	0.1472	1472	1122	1822
Monterey	NC	NC	NC	NC
Mount Washington	NC	NC	NC	NC
New Ashford	0.1852	1852	387	3317
New Marlborough	0.1869	1869	1130	2608
North Adams	0.1358	1358	1160	1557
Otis	0.1782	1782	1036	2529
Peru	0.2000	2000	943	3057
Pittsfield	0.1057	1057	959	1155
Richmond	0.0608	608	223	993
Sandisfield	0.0845	845	198	1492
Savoy	NC	NC	NC	NC
Sheffield	0.1073	1073	716	1429
Stockbridge	0.1209	1209	539	1879
Tyringham	NC	NC	NC	NC
Washington	0.2000	2000	675	3325
West Stockbridge	0.1798	1798	1000	2596
Williamstown	0.1201	1201	903	1499
Windsor	0.0694	694	107	1282
Berkshire County	0.1245	1245	1181	1309
Housatonic River Area	0.1150	1150	1070	1229

CI = 95% Confidence Interval

NC = Not Calculated. Prevalence is not calculated where the numerator is less than 5, due to instability of the rate.

Bolded cities/towns = cities/towns located in the Housatonic River Area

Period Prevalence Rate Calculation: All DOE IEP Students / All Students Enrolled (ages 3-10 years old)

TABLE 7: Period Prevalence Rate Calculations for Subgroup DOE IEP Students (3-10 years old)

Berkshire County cities/towns	Prevalence	Prevalence per10,000	Lower CI per10,000	Upper CI per10,000
Adams	0.7302	7302	6527	8077
Alford	NC	NC	NC	NC
Becket	0.5517	5517	3707	7327
Cheshire	0.7692	7692	6370	9015
Clarksburg	0.8333	8333	6225	10442
Dalton	0.6267	6267	5172	7361
Egremont	NC	NC	NC	NC
Florida	0.7000	7000	4160	9840
Great Barrington	0.7500	7500	6221	8779
Hancock	NC	NC	NC	NC
Hinsdale	0.7200	7200	5440	8960
Lanesborough	0.5926	5926	4073	7779
Lee	0.8136	8136	7142	9129
Lenox	0.6379	6379	5142	7616
Monterey	NC	NC	NC	NC
Mount Washington	NC	NC	NC	NC
New Ashford	NC	NC	NC	NC
New Marlborough	0.8000	8000	6247	9753
North Adams	0.8323	8323	7734	8911
Otis	0.6667	6667	4489	8844
Peru	0.7273	7273	4641	9905
Pittsfield	0.8678	8678	8347	9010
Richmond	0.7778	7778	5062	10494
Sandisfield	NC	NC	NC	NC
Savoy	NC	NC	NC	NC
Sheffield	0.8387	8387	7092	9682
Stockbridge	1.0000	10000	10000	10000
Tyringham	NC	NC	NC	NC
Washington	NC	NC	NC	NC
West Stockbridge	0.8750	8750	7129	10371
Williamstown	0.5273	5273	3953	6592
Windsor	1.0000	10000	10000	10000
Berkshire County	0.7710	7710	7479	7941
Housatonic River Area	0.8017	8017	7723	8311

CI = 95% Confidence Interval

NC = Not Calculated. Prevalence is not calculated where the numerator is less than 5, due to instability of the rate.

Bolded cities/towns = cities/towns located in the Housatonic River Area

Period Prevalence Rate Calculation: Subgroup of DOE IEP Students / All DOE IEP Students (ages 3-10 years old)

APPENDIX A:

DESCRIPTION OF EARLY INTERVENTION INFORMATION SYSTEM FORMS

1. EIIS Referral Form- This form is filled out at the initial intake visit when a child is referred for services between the ages of 0 and three years old. If the family agrees the program goes on to evaluate the child for eligibility of EI services. If the family declines a discharge form is completed.
2. EIIS Evaluation Form- This form is completed to evaluate a child's eligibility. The child receives a multidisciplinary evaluation within 45 days of the child's referral. Using an assessment tool the assessor conducts tests to determine the child's development level, established (biological) risk factors, and social environmental risk factors. If the child is determined to be eligible a multidisciplinary team assesses the child. If the child meets defined criteria for eligibility they are able to receive services for one year, eligibility determined annually. If the child does not meet defined criteria for eligibility, but qualifies for services by "clinical judgment" eligibility must be reassessed at 6 months. This form is not completed every time the child is seen and does not include ongoing assessment information.
3. EIIS IFSP Form- An Individualized Family Service Plan is developed and then the child receives the services agreed upon.
4. EIIS Discharge Form- This form is completed at any point when the child is no longer involved with the EI Program.

APPENDIX B:

DOE IEP - SCHOOL DISTRICT PARTICIPATION LOG

Cities/Towns by District	# of Packets Mailed by Districts	% Participation Per District
Adams, Cheshire	177	**26%**
Alford, Egremont, Monterey, New Marlborough, Sheffield	NP	**NP**
Becket, Dalton, Hinsdale, Peru, Washington, Windsor	225	**30%**
Clarksburg, Florida, Savoy	43	**28%**
Great Barrington, Stockbridge, West Stockbridge	86	**30%**
Richmond, Hancock, Lanesborough, New Ashford	83	**37%**
Lee, Tyringham	54	**33%**
Lenox	117	**29%**
North Adams	125	**36%**
Otis, Sandisfield	23	**30%**
Pittsfield	289	**30%**
Williamstown	103	**33%**
Total for Berkshire County	**1325**	**31%**

% Participation = Total # of YES Consents Returned / Total # of Consent Packets Mailed

NP = Non-participating district