

MEMORANDUM OF AGREEMENT BETWEEN
FAMILY POLICY COMPLIANCE OFFICE
OFFICE OF MANAGEMENT
UNITED STATES DEPARTMENT OF EDUCATION
AND
OFFICE OF SPECIAL EDUCATION PROGRAMS
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES
UNITED STATES DEPARTMENT OF EDUCATION
AND
CENTERS FOR DISEASE CONTROL AND PREVENTION
PUBLIC HEALTH SERVICE
UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES

This agreement, made the 11th day of Dec., 2000, between the Family Policy Compliance Office (FPCO), Office of Management (OM), the U.S. Department of Education (ED) and the Office of Special Education Programs (OSEP), the Office of Special Education and Rehabilitative Services (OSERS), the U.S. Department of Education (ED) and the National Center for Environmental Health (NCEH), Centers for Disease Control and Prevention (CDC), Public Health Service (PHS), U.S. Department of Health and Human Services (HHS). The purpose of this agreement is to designate the CDC as an "authorized representative" of ED for purposes of collecting information under the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP or Program).

RECITALS:

1. The CDC has tracked the population-based prevalence of children with developmental disabilities since 1984. Since 1991, CDC has gathered this information as part of the MADDSP. Under the Program, CDC gathers information from both health and education records of students with disabilities.
2. In implementing the MADDSP, CDC reviews the education records of public school students in the metropolitan Atlanta region to track students with developmental disabilities. Researchers go into schools, review student files, and obtain relevant information on the nature of the disability and associated disability services. The Program focuses on children from ages 3 to 10 years. The MADDSP is the only population-based surveillance system for children with multiple developmental disabilities in the United States. The Program provides the only means of estimating the prevalence of disabilities such as autism, cerebral palsy, mental retardation and hearing and visual impairments in children.
3. The Family Educational Rights and Privacy Act (FERPA) generally prohibits the disclosure of education records without the consent of the parent for children under the age of 18.

Under FERPA, education records are defined as records directly related to a student and maintained by the school. The records accessed by the CDC at metropolitan Atlanta public schools are education records, and subject to FERPA.

4. FERPA contains several exceptions to the general rule that education records may not be disclosed without prior, written parental consent. One exception allows for disclosures to authorized representatives of the Secretary of Education. Such a disclosure must be made in connection with an audit or evaluation of a Federal or State supported education program. The disclosure may also be made for the enforcement of or compliance with Federal legal requirements related to the Federal or State education program.
5. ED currently uses information from the MADDSP in two ways. The OSEP uses the data from the MADDSP to establish indicators for its performance in meeting the requirements of IDEA. Specifically, the OSEP uses the data from the MADDSP to measure its performance under Part C of the Individual with Disabilities Act (IDEA) as required by the Government Performance Reporting Act (GPRA). Second, relying on the MADDSP data, OSEP awards grants for blind and hearing impairment programs.
6. In December 1999, LeRoy Rooker, the director of the FPCO, informally advised the Atlanta Metropolitan Regional Education Service Agency that the CDC's efforts in gathering information from schools for the MADDSP would not generally be authorized under FERPA. In February 2000, the CDC wrote ED and asked the Department to make the CDC an authorized representative of the Department.
7. ED, based on a recommendation of the FPCO, has concluded that the CDC should be designated an authorized representative for purposes of information collection under the MADDSP.
8. Without continued access to these records, the MADDSP will not be able to provide meaningful estimates of the occurrence of developmental disabilities in children. Without this Program, there will be no population-based prevalence estimates or description of the possible factors affecting the capabilities of children with these disabilities.


AGREEMENT:

1. ED designates the CDC as its "authorized representative" under FERPA. This authorization is limited to the collection of information and data from the education records (as defined by FERPA) of public school students in metropolitan Atlanta as necessary for the CDC to administer the MADDSP.
2. CDC agrees to share, upon request by OSEP, all data collected for the MADDSP with ED. The data submitted to ED must be in non-personally identifiable, aggregate form.
3. CDC agrees that all personally identifiable information gathered from the education records of students at public schools in metropolitan Atlanta will be protected from further redisclosure to any third party in personally identifiable form. CDC further agrees that

personally identifiable information from these records will not be disclosed to anyone other than those officials working directly with the MADDSP.

4. CDC agrees to destroy all personally identifiable student information obtained from the above-referenced education records as soon as all statistical analysis has been performed, or when the information is no longer needed, whichever date comes first. All versions of such information and data, electronic, paper, or otherwise, must be destroyed.
5. CDC agrees to work together with the FPCO to ensure that every school providing access to and/or disclosing education records for the MADDSP will record such disclosures as required by FERPA. CDC further agrees that it will work with the FPCO to ensure that every school providing access to and/or disclosing education records for the MADDSP will update its annual notification to include the CDC as a recipient of education records.

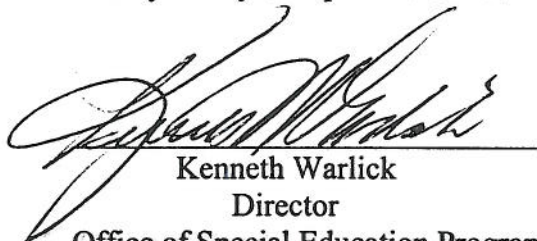
This agreement shall be in effect for five years from the date of the last signature. OSEP agrees to notify the FPCO on a yearly basis, on or by 30th day of September, that it continues to use the information from the MADDSP for the purposes discussed above in paragraph five of the recital section. Such notification shall be made to the Director of the FPCO by the Director of OSEP or his or her designee, and shall be made in writing, including through electronic mail.



LeRoy Rooker
Director
Family Policy Compliance Office

12/11/00


Date



Kenneth Warlick
Director
Office of Special Education Programs

11/30/00

Date



Coleen Boyle
Director
Division of Birth Defects, Child
Development and Disability and Health
National Center for Environmental Health

11/17/00

Date