



**Testimony of the
Centers for Disease Control and Prevention (CDC)**

**On
HIPAA Privacy Rule and the Family Educational
Rights and Privacy Act Impact on Public Health
Practice**

Prepared by the
CDC Health Information Privacy Office
For the Office of the Director

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**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Good morning ladies and gentlemen, members of the sub-committee. My name is Beverly Dozier. I am the HIPAA Privacy Rule Coordinator for the Centers for Disease Control and Prevention (CDC). My position is within the newly created Health Information Privacy Office (HIPO), an office within CDC's Epidemiology Program Office (EPO).

I was asked to speak this morning about the implications and impact on public health of the nexus between the Privacy Rule and the Family Educational Rights and Privacy Act of 1974 (FERPA). As you know, all records protected by FERPA are excluded from the definition of protected health information in the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Therefore, regardless of the nature of the information contained in an education record protected by FERPA, even if it is health-related, the law governing the privacy of those records is FERPA and not the HIPAA Privacy Rule.

The CDC has several national health surveillance programs that track various childhood health conditions and behaviors. A few examples are: the National Immunization Program; the National Center On Birth Defects and Developmental Disabilities, which tracks conditions such as Birth Defects, Attention Deficit Hyperactivity Disorder, Fetal Alcohol Syndrome and Autism; the National Center for Injury Prevention and Control, which has systems to track data related to unintentional injury and violence and collects data related to behavior risks for injuries and violence; the National Center for Environmental Health tracks Child Lead Poisoning, Asthma, and conducts the National Environmental Tracking Program; and the National Center for Chronic Disease Prevention and Health Promotion, Division of Adolescent and School Health, Division of Nutrition and Physical Activity, and the Office on Smoking and Health. In addition, CDC funds a host of external partners, including state and local health departments, hospitals, and academic institutions, to identify and track these and other childhood health conditions.

Several provisions of the Privacy Rule permit covered entities to provide protected health information to public health authorities such as the CDC without the consent or authorization of the individual.¹ These provisions were included in the Privacy Rule because the Department of Health and Human Services understands the need to balance individual privacy interests with public needs to acquire health data for public health and other purposes. For some nation wide health surveillance projects, public health authorities strongly believe that accurate data on the incidence of health conditions could not be obtained if consent or authorization were required. This is especially true of the types of conditions that CDC tracks in children. Often a parent is reluctant to have a child “labeled” with a condition or a developmental disability. For this reason, and some other socio-economic factors, obtaining accurate data for these types of conditions would be unattainable if parental consent is required.

There has been some confusion in state and local education institutions about whether FERPA or HIPAA protects health information in the case where a school runs a health clinic. For example, when a school has a health clinic that is a covered entity under the Administrative Simplification Regulations under HIPAA because it provides health care and conducts electronic transactions, as defined in the Transactions Rule; and these health records are determined by the school to be protected by FERPA, then the records would not also be protected by the Privacy Rule. While covered entities under the Privacy Rule may disclose protected health information to public health authorities for public health activities, FERPA does not generally allow a school or school system to share health information contained in education records covered by FERPA with a public health authority without parental consent.² Conversely, a public health authority is

¹ 45 CFR 164.512

² 20 U.S.C. 1232g (b)(1), and 20 U.S.C. 1232g(b)(3)

permitted under the Privacy Rule (subject to state and federal laws) to share the data it collects with health care providers, public health authorities, and the school system, if needed.

Some of the childhood conditions that CDC and its partner's track are uniquely identified in school-age children. In many cases children with these conditions are often only identified by the school. For example, autism and attention deficit hyper-activity disorder either do not appear, or are not recognized until the child is of school age. These conditions manifest in the child as behaviors, and the school psychologist or other specialist usually test the child, not to make a diagnosis, rather to determine what kinds of interventions would assist the child in being more effective in accomplishing school work. The results and conclusions of these tests become part of the child's school records, and are thus protected by FERPA. Furthermore, these results are seldom found ascertained in the clinical setting.

Under an exception in the FERPA regulations that permits disclosure of education records to authorized representatives of the Department Of Education (ED), CDC has a memorandum of understanding (MOU) with ED. This MOU allows CDC access to educational records in 5 metropolitan Atlanta counties for the Metropolitan Atlanta Developmental Disabilities Surveillance Project. The MOU expires next year. Data from the CDC's surveillance of autism in metropolitan Atlanta in 1996 show that for 40% of the children identified with autism, information was found on these children only at the school sources. Only 3% of the children were found uniquely at clinic sources. So, while 57% of the children with autism were known to school and clinic sources, school sources provided a great deal of unique information on the features of the children's disabilities.³ There is no national policy that allows for the

³ Public Health Monitoring Of Developmental Disabilities With A Focus On The Autism Spectrum Disorders

sharing of health data and information between the public health authorities and educational institutions. It is vitally important to the health of the nation's children that public health authorities and educational institutions work together to identify childhood conditions, the incidence of childhood conditions, and find effective interventions and preventions.

Congress recently passed the Birth Defects and Developmental Disabilities Prevention Act of 2003, Public Law 108-154, which provides an opportunity for HHS and ED to work together to resolve this data-sharing dilemma as it relates to autism and other developmental disabilities surveillance. The law requires HHS and ED to study these issues and submit a report to Congress within 18 months. The report must describe (1) the challenges to obtaining education records (in the absence of parental or patient consent) for public health purposes like surveillance data for autism and other developmental disabilities; (2) how these challenges can be overcome, including efforts to educate parents, improve public confidence in the privacy of public health surveillance programs, and raise the rates of parental or patient consent. The report will also include specific quantitative and qualitative justifications for any recommendations for changes to existing statutory authority-including the Family Educational Rights and Privacy Act of 1974.

CDC looks forward to working together with ED to protect the health information privacy of individuals while maintaining a strong public health system, and clarifying the provisions of the Privacy Rule as they relate to public health and education.