



*Family Educational Rights  
and Privacy Act  
of 1974 (20 U.S.C. 1232g) (FERPA)*

Public Health Experience at CDC-  
Background and History

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# FERPA



- ◆ Protects students' privacy for educational records
- ◆ Records generally cannot be released or accessed without parental consent
- ◆ Gives parents the right to access and make corrections to student records

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# FERPA



- ◆ Applies to all educational institutions which receive funding from the Federal Department of Education (USED)
- ◆ Applies to entire content of the student's educational record

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# FERPA



- ◆ Educational Record is defined as:
  - Directly related to the student
  - Maintained by an educational agency or institution

Please note that this definition is not content based.

Possession is the law.

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# FERPA



## ◆ Disclosure:

- Means to permit access to or the release, transfer, or other communication of personally identifiable information contained in educational records of any party, by any means, including oral, written, or electronic means.
- 20 USC 1232g

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# FERPA



- ◆ Under what conditions is prior consent not required to disclose information?
  - The disclosure is to State and local educational authorities, or
  - The disclosure is to organizations conducting studies for, or on behalf of, educational agencies or institutions to:
    - Develop, validate, or administer predicative tests
    - Administer student aid
    - Improve instruction

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# FERPA



- ◆ CDC has an MOU with the Federal Department of Education: December 11, 2000 for 5 years, expires 2005
  - Autism and Developmental Disabilities surveillance
  - Designates CDC as an “authorized representative” of USED
  - Data are used by the USED to measure its performance under Part C of IDEA as required by the Government Performance and Results Act

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# FERPA



## ◆ CDC MOU continued

- CDC now supports autism spectrum disorder monitoring programs in 17 states, in addition to its own model monitoring program based in Atlanta, Georgia
- Some states began collecting data by obtaining state level MOUs modeled after the CDC MOU with USED

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# FERPA



## ◆ CDC MOU continued:

- In February 2004, USED's Family Policy Compliance Office sent responses to inquiries from CDC-funded state projects regarding their proposed activities. The responses indicated that the projects utilizing school records without individual parental consent would not be compliant with FERPA.

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# FERPA



- ◆ CDC and representatives from the Department of Health and Human Services, and from USED met on May 12, 2004 in DC to discuss alternative solutions that would allow continued surveillance of autism utilizing health information from school records

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# FERPA



## ◆ Options Discussed May 12, 2004

- incorporating passive consent for record review into the Individual Evaluation Plan (IEP) process that schools oversee
- incorporating passive consent into the consent for services process that occurs prior to the IEP process
- conducting or permitting state or local education agencies to conduct the needed record reviews within the context of program assessment or evaluation.

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# FERPA



- ◆ In February 2005, CDC was informed by USED that none of these options were acceptable.

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# FERPA



- ◆ On December 3, 2003, the President signed the Birth Defects and Developmental Disabilities Prevention Act of 2003. Specifically, the Act states:
  - *Not later than 18 months after the date of enactment of this Act, the Secretary of Health and Human Services jointly with the Secretary of Education shall submit to the House of Representatives a report concerning CDC surveillance activities and FERPA*

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# FERPA Report to Congress



- ◆ *The report required among other things:*
    - *a description of the efforts taken by the Centers for Disease Control and Prevention to utilize education records in conducting the surveillance program while obtaining parental or patient consent for such education records, including the outcomes of such efforts;*
    - *a description of the challenges provided to obtaining education records in the absence of parental or patient consent for the purpose of obtaining additional surveillance data for autism and other developmental disabilities;*
- and*

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# FERPA Report to Congress



## ◆ The Report required:

– *A description of the manner in which such challenges can be overcome, including:*

- *efforts to educate parents, increase confidence in the privacy of the surveillance program, and increase the rate of parental or patient consent, and **including specific quantitative and qualitative justifications for any recommendations for changes to existing statutory authority, including the Family Educational Rights and Privacy Act of 1974***

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# FERPA Report to Congress



- ◆ Requests recommendations on resolving the FERPA access to records problem
- ◆ HIPAA has a public health provision which allows access to surveillance data without consent
- ◆ Health information in educational records is protected by FERPA
- ◆ Information protected by FERPA is not covered by HIPAA

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# FERPA



◆ Health and Education must find a way to work together for the benefit of the nation's children and for the public's health

– Consent from parents?

- Send home flyers
- Sign up at registration?

– Regulation change?

- HIPAA?
- FERPA?

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# FERPA



✦ For more information or assistance, please contact:

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