Enhancing Communication Among Health Care and Educational Programs

How Privacy Regulations Impact Delivery of Effective Services

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Three Main Privacy Laws

Health Insurance Portability and Accountability Act (HIPAA)

- Title II, Privacy Rule
- Protected health information use by covered entities

Family Educational Rights and Privacy Act (FERPA)

- Entities receiving U.S. Department of Education Funds
- . Confidentiality of "education records"

Part C Regulations

- IDEA
- B-3 early intervention population

FERPA

 Signed consent IS needed for programs with Dept of Education funding to share Educational Records with personally identifiable information

The definition of "Educational records" includes any health information in the possession of the educational agency such as health-related IEP information for children served under IDEA

- Signed consent IS NOT needed:
 - To disclose general contact information, enrollment status, honors, and attendance; OR in cases of health/safety emergencies
 - Annual notification of intent to share above information is required

HIPAA

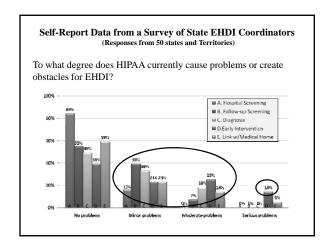
- Covered entity: A health plan, clearinghouse, or health care provider who bills for provision of services ("conducts financial and administrative transactions electronically").
- Protected Health Information (PHI): Individually identifiable health information transmitted or maintained by covered entities
- Sharing information
 - Signed consent required to use PHI for marketing or research
 - Signed consent is NOT required:
 - For health providers to exchange information for treatment, payment, health care operations.
 - To share information for Public Health purposes
 - Providers must keep a record of information that is share

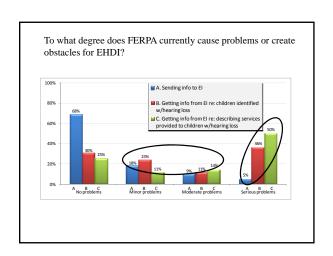
Part C Privacy Regulations

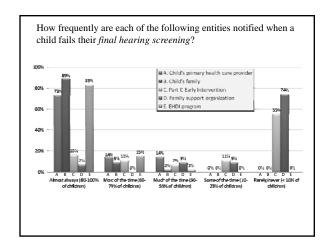
- Signed consent IS needed for Part C to share any personal information with "non-participating providers" (i.e., entities outside the Part C system)
- Signed consent IS NOT needed for anyone to refer a child to Part C (name, contact info, reason for referral)
- Signed consent IS NOT needed for Part C to share info with "participating providers"
- Part C is more restrictive than either HIPAA or FERPA

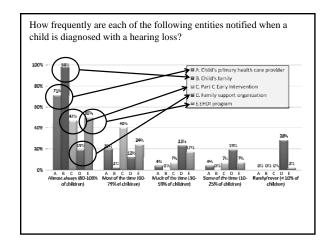
• State laws can:

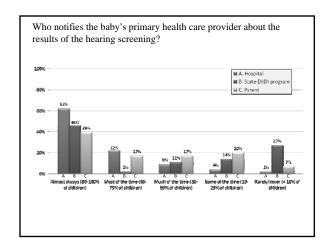
- Provide MORE privacy protections, but not less (i.e., state laws seldom, if ever, enable sharing of education/health related information that is not already allowed under HIPAA, FERPA and/or Part C
- Encourage reporting

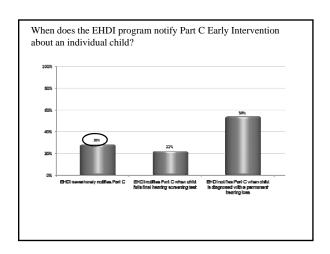


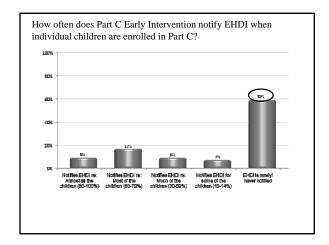


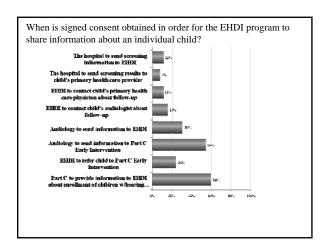












Impact of Federal Privacy Regulations on:

- Hearing Screening
- Diagnostic Evaluations
- Early Intervention
- Linkages with Medical Home and other health care providers
- Family Support programs

Federal Privacy Regulations Related to:

Hearing Screening

HIPAA

- Written consent NOT needed for hospitals and/or health care providers to share hearing screening information with EHDI programs, other health care providers and/or Part C, because screening information:
 - Is needed for public health activities (e.g., surveillance, program improvement, etc)
 - Is needed for facilitating ongoing health care
- \checkmark Documentation required whenever information is shared

FERPA

✓ Does not apply until children are enrolled in programs that receive federal education funding.

Part C Privacy Regulations

- ✓ Does not apply until children are referred to Part C
- Once children are referred to Part C, any information possessed by the Part C cannot be shared with non participating entities without written consent

Federal Privacy Regulations Related to:

Diagnostic Evaluations

HIPAA

- Written consent NOT needed for health care providers to share Dx info with EHDI programs, other health care providers, and/or Part C, because such information:
 - Is needed for public health activities
 - Is needed for facilitating ongoing health care

FERPA

 Written consent required for education agencies to share Dx info with nonparticipating entities.

■ Part C Privacy Regulations

✓ Written consent required to share Dx info with non-participating entities

Federal Privacy Regulations Related to:

Early Intervention Services

HIPAA

- \checkmark Does not generally apply to sharing EI info among EHDI stakeholders
- ✓ Health care providers should be part of IFSP team

FERPA

- Written consent required for education agencies to share El info with non-participating entities except that
 - General contact and enrollment info can be shared if parents are informed at least annually about the intent to share such info and given opportunity to object

Part C Privacy Regulations

- Written consent required to share any EI info with non-participating entities (Part C is more restrictive than FERPA)
- Although not legally tested, some states have designated EHDI programs as "participating agencies" which does allow sharing of information among Part C and EHDI without written consent

Federal Privacy Regulations Related to:

Medical Home and Other Health Care Providers

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- Written consent NOT needed for sharing of info among health care provider (e.g., medical home, geneticist, audiologist, physical therapist, etc) EHDI programs, and/or Part C when such information:
 - . Is needed for public health activities
 - Is needed for facilitating ongoing health care
- ✓ Documentation of shared information is required

■ EFRDA

✓ Written consent required for education agencies to share info w/ health care
providers (many health care providers complain about sending info to a "black hole")

■ Part C Privacy Regulations

- ✓ Part C cannot share info with health care providers without written consent
- ✓ Hard to imagine a situation where a health care provider would be considered a "participating entity."
- ✓ Entities that have legally received Part C information must abide by privacy regulations when sharing that information with others.

Federal Privacy Regulations Related to:

Family Support Programs

HIPAA

 Health care providers must have written consent to share info with Family Support programs because info is not needed for public health activities or to facilitate ongoing health care

FERPA

 Once children have been referred to programs that receive federal education funding, written consent required for info to be shared

Part C Privacy Regulations

- ✓ Some states have designated Family Support programs as "participating agencies" in the Part C system, thus enabling sharing of information without written consent
- √ Information possessed by the Part C system cannot be shared with nonparticipating entities without written consent





Recommended Strategies

- 1. Well informed families who are given own copies of consents and medical/educational records to share as needed
- Coordinated consent forms (and training) so that a single signature can give permission to share info with broad array of providers.
 - Ideally, consent would be obtained when newborn hearing screening is failed
- Memoranda of Agreement (MOA's) among EHDI, Part C, Family Support Programs and others
- 4. Designation of "participating agencies" as part of Part C system.
 - ✓ Inclusion in Part C State plan
 - ✓ Memoranda of Agreement and inclusion in Part C State Plan
 - Clear responsibility for significant role MULTIPLE components และ Components และ Components และ Components (March 2014)

Recommended Strategies (continued)

- 5. State laws that require reporting do not remove Federal privacy protections but may encourage better reporting
- Obtain written permission from parents as part of IFSP/IEP document to share information with relevant agencies
- Integrate computer-based public health information systems (e.g., immunization, blood-spot screening, hearing screening) and include info about ervices provided to children with special health care needs

Enhancing communication among health care and educational programs while conforming with federal privacy laws and regulations (according to Leonardo da Vinci)

"Life is pretty simple: You do some stuff. Most fails. Some works. You do more of what works. If it works big, others quickly copy it. Then you do something else. The trick is the doing something else."

