EHDI Challenges and Strategies in Addressing Privacy Regulations

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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
Why is it Important to Understand Privacy Regulations?

- Ensure children with failed screening are not lost to follow-up
- Help families access needed services—fast!
- Improve coordination with medical home and others
- Provide comprehensive surveillance data and measure outcomes
HIPAA Terms

- **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**: Individually identifiable health information transmitted or maintained by covered entities.
HIPAA Says....

• 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, e.g., EHDI
  – Providers must keep a record of information shared
FERPA Says....

• Signed consent is needed for programs with Dept of Educ funding to share Educational Records with personally identifiable information

• Educational records includes health information for children served under IDEA

• Signed consent is NOT needed:
  – To disclose general contact information, enrollment status, honors, attendance, in cases of health/safety emergencies
  – Annual notification of intent to share above information is required
Part C Privacy Regs Say….  

- Signed consent needed for Part C to share any personal information “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 has more privacy protections than FERPA and HIPAA
• State mandates for reporting seldom enable sharing of EHDI related data that is not already allowed under HIPAA, FERPA or Part C

• State laws can:
  – provide MORE privacy protections, but not less
  – Encourage reporting
Results From Self-Report Survey of EHDI Coordinators

n=47 states, 3 territories
To what degree does HIPAA currently cause problems or create obstacles for EHDI?
To what degree does FERPA currently cause problems or create obstacles for EHDI?
How frequently are each of the following entities notified when a child fails their final hearing screening?
How frequently are each of the following entities notified when a child is diagnosed with a hearing loss?
Who notifies the baby’s primary health care provider about the results of the hearing screening?
When does the EHDI program notify Part C Early Intervention about an individual child?
How often does Part C Early Intervention notify EHDI when individual children are enrolled in Part C?

- Notifies EHDI re: Almost all the children (80-100%): 9%
- Notifies EHDI re: Most of the children (60-79%): 17%
- Notifies EHDI re: Much of the children (30-59%): 9%
- Notifies EHDI for some of the children (10-14%): 7%
- EHDI is rarely/never notified: 59%
When is signed consent obtained in order for the EHDI program to share information about an individual child?
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
  - 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 system 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 non-participating entities.

- **Part C Privacy Regulations**
  - Written consent **required** to share Dx info with non-participating entities

- **State reporting mandates** may encourage providers, but cannot over-rule Federal Privacy Regulations. State laws can add, but not remove privacy protections
Federal Privacy Regulations Related to Early Intervention Services

- **HIPAA**
  - Does not generally apply to how early EI info is shared among EHDI stakeholders
  - Health care providers should be part of IFSP team

- **FERPA**
  - Written consent required for education agencies to share EI 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 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

- **HIPAA**
  - Written consent NOT needed for reciprocal sharing of info among health care providers (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 required whenever information is shared

- **FERPA**
  - 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
  - Information possessed by the Part C system cannot be shared with non-participating entities without written consent
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
  - ✓ 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**
  - ✓ 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 non-participating entities without written consent
Recommended Strategies

- Well informed families who are given own copies of consents and medical/educational records to share as needed

- Coordinated consent forms (and training) to facilitate info sharing with broad array of providers.
  - Ideally, consent would be obtained when newborn hearing screening is failed, but there issues to be addressed

- MOA’s and designation of “participating providers” under Part C system

- State laws mandating reporting to EHDI and Medical Home
  - Doesn’t remove Federal privacy protections but may encourage better reporting

(continued....)
Recommendations (continued)

• Signatures obtained on IFSP to share document
• Families should be informed early about family support, multiple “doors” for accessing
• Public health data systems that contain info about services provided to children with hearing loss should be maintained
Next Steps

- Review DRAFT document and give us feedback
- Send examples of consent forms, MOAs, etc to be posted on [www.infanthearing.org](http://www.infanthearing.org) to be a resource for others
Thank You!

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