

# **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., EHCI**
  - **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**

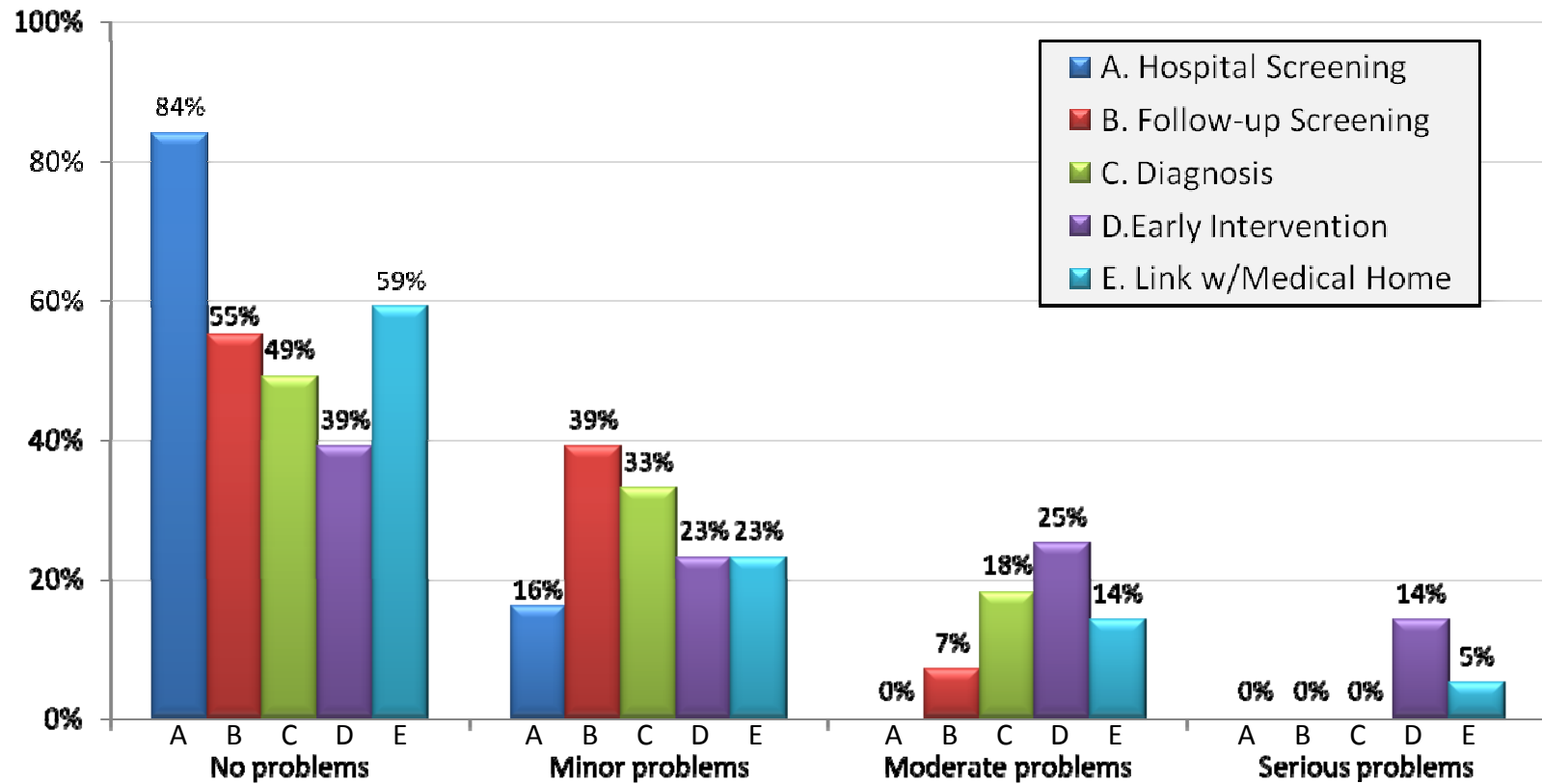
- **State mandates for reporting seldom enable sharing of EHDI related data that is not already allowed under HIPAA, FERPA or Part C**
- **State laws can:**
  - **provide MORE privacy protections, but not less**
  - **Encourage reporting**



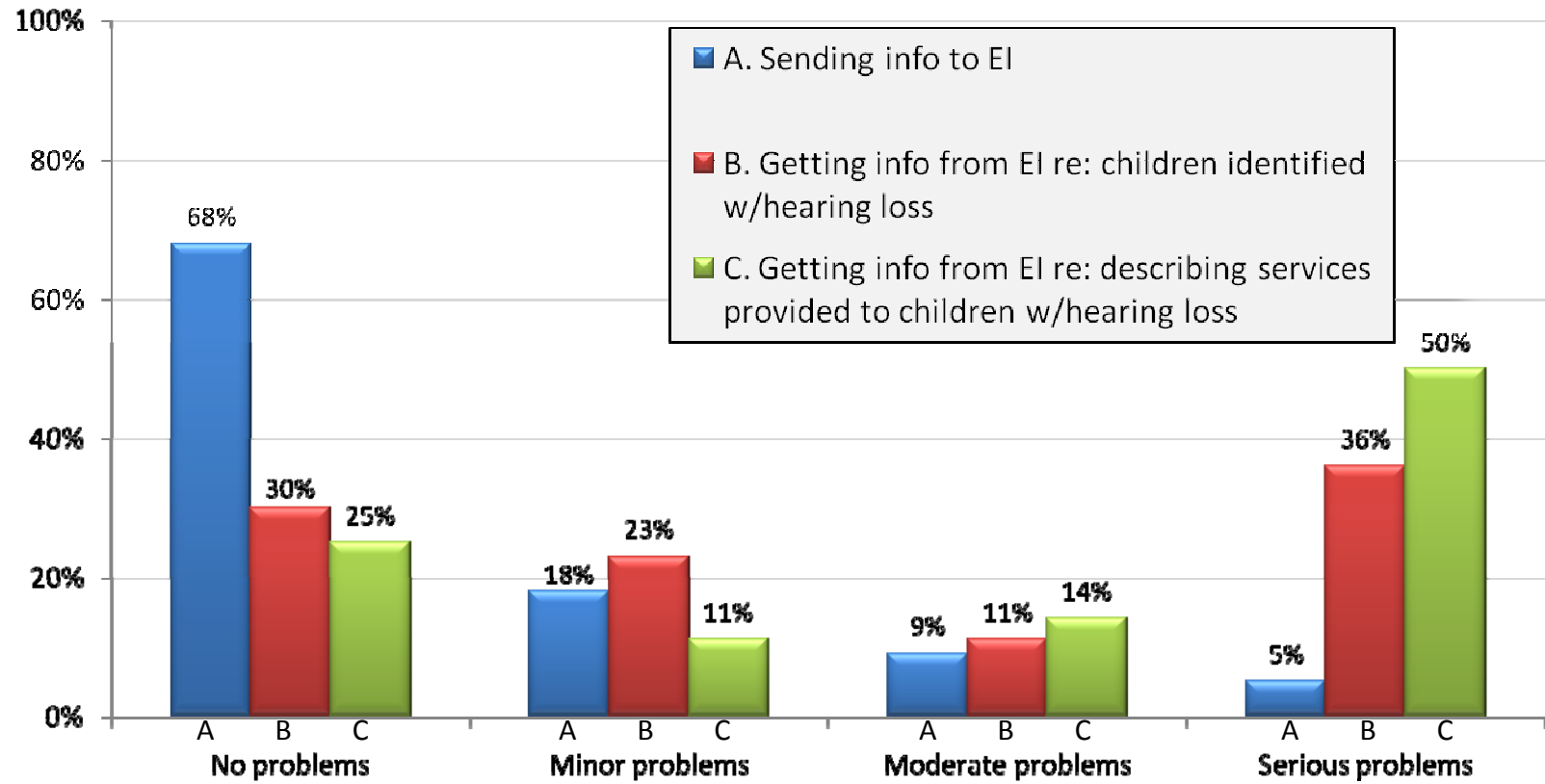
# Results From Self-Report Survey of EHDI Coordinators

n=47 states, 3 territories

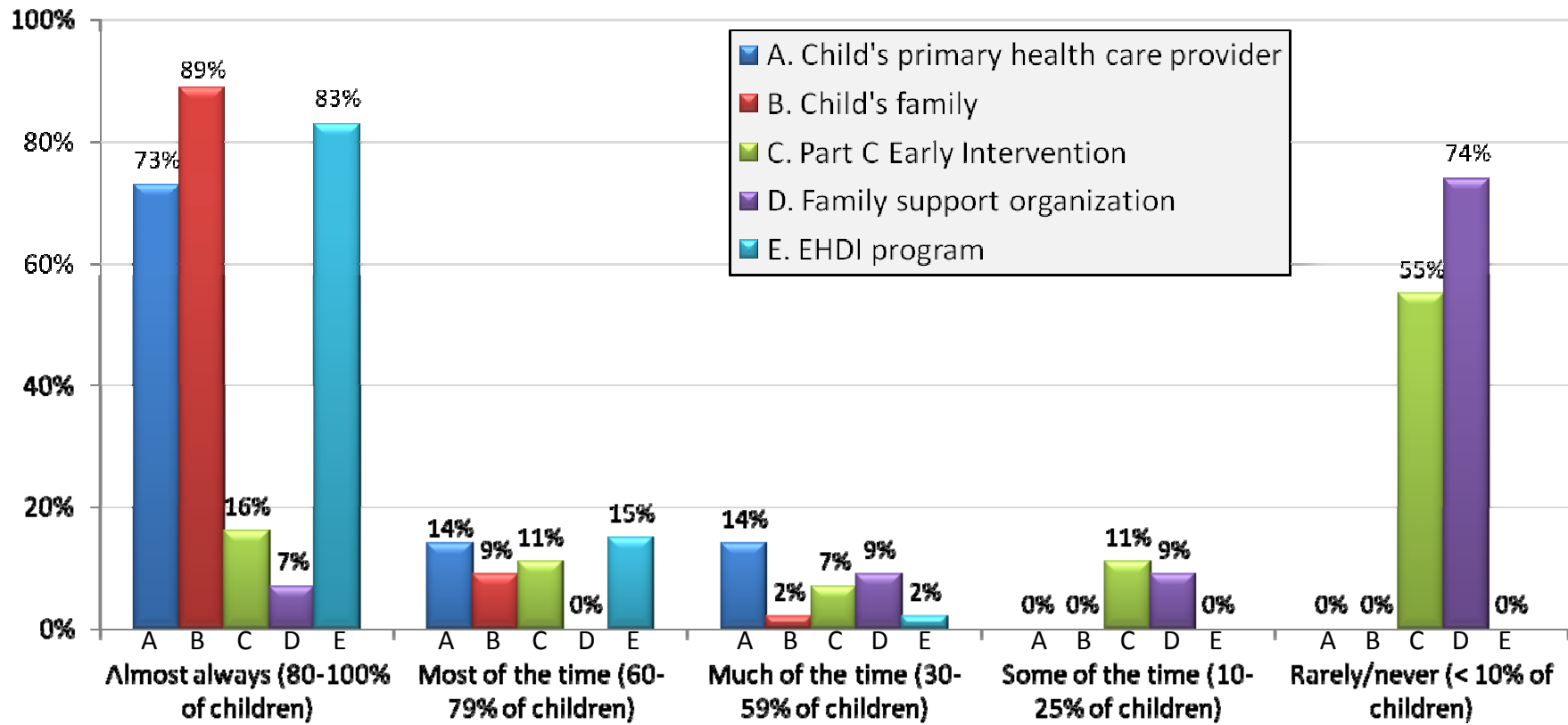
# To what degree does HIPAA currently cause problems or create obstacles for EHDI?



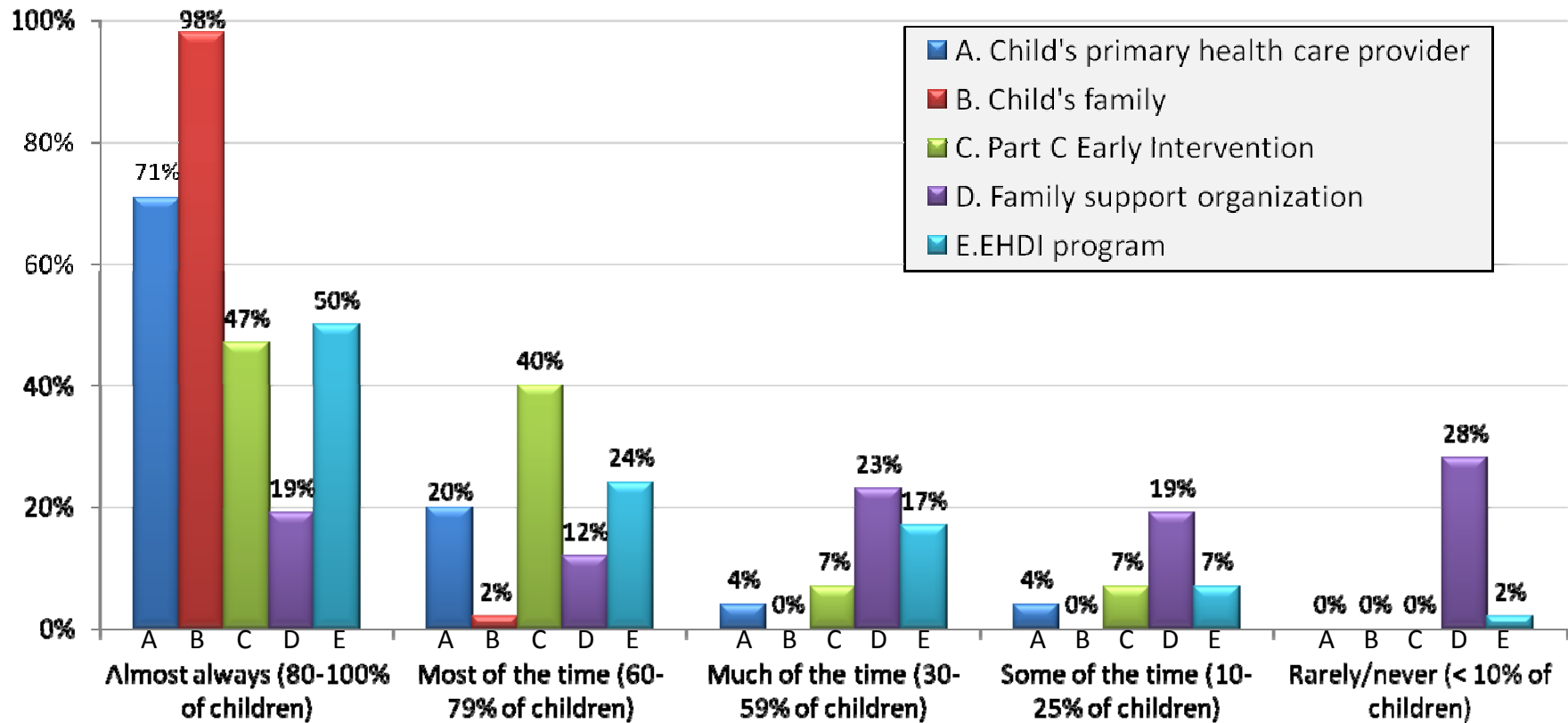
# To what degree does FERPA currently cause problems or create obstacles for EHDI?



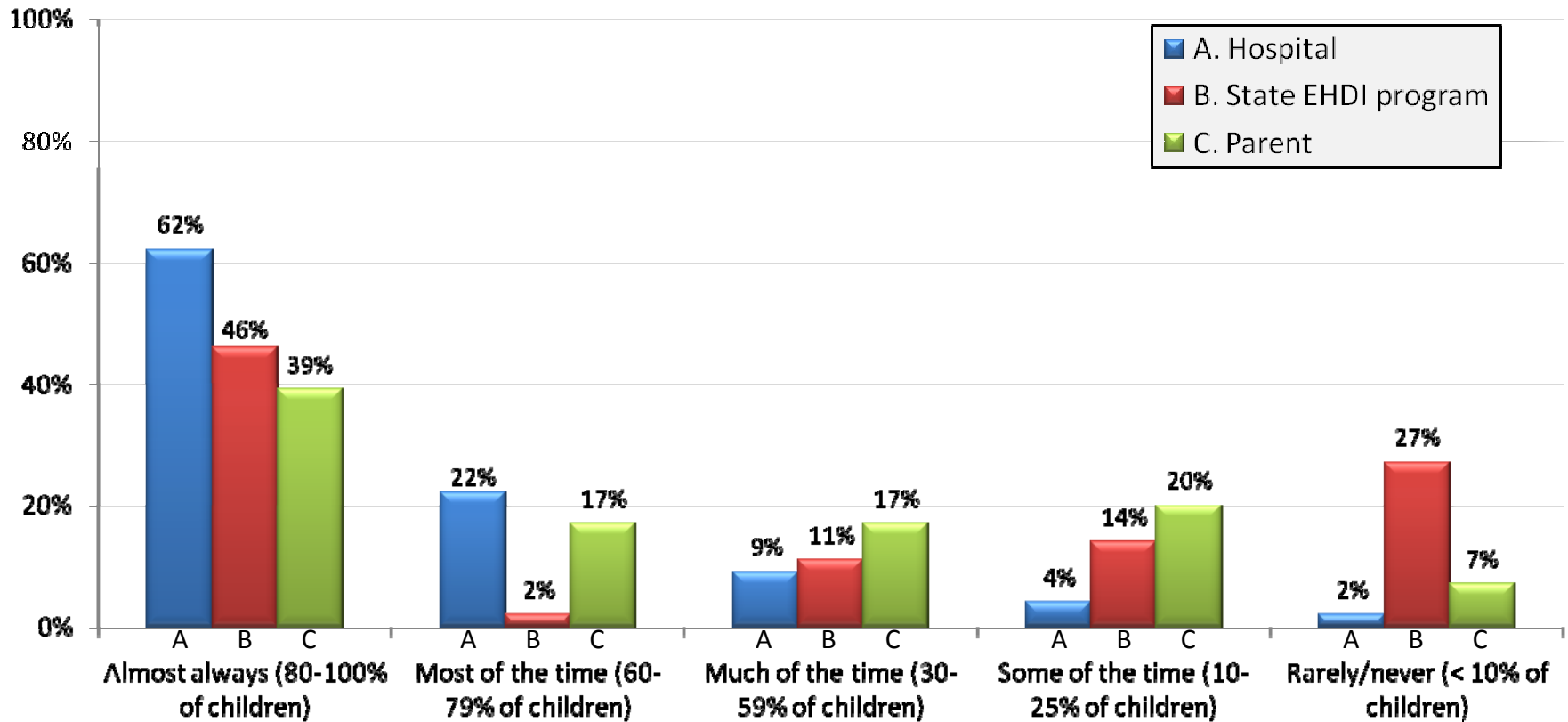
## How frequently are each of the following entities notified when a child fails their *final hearing screening*?



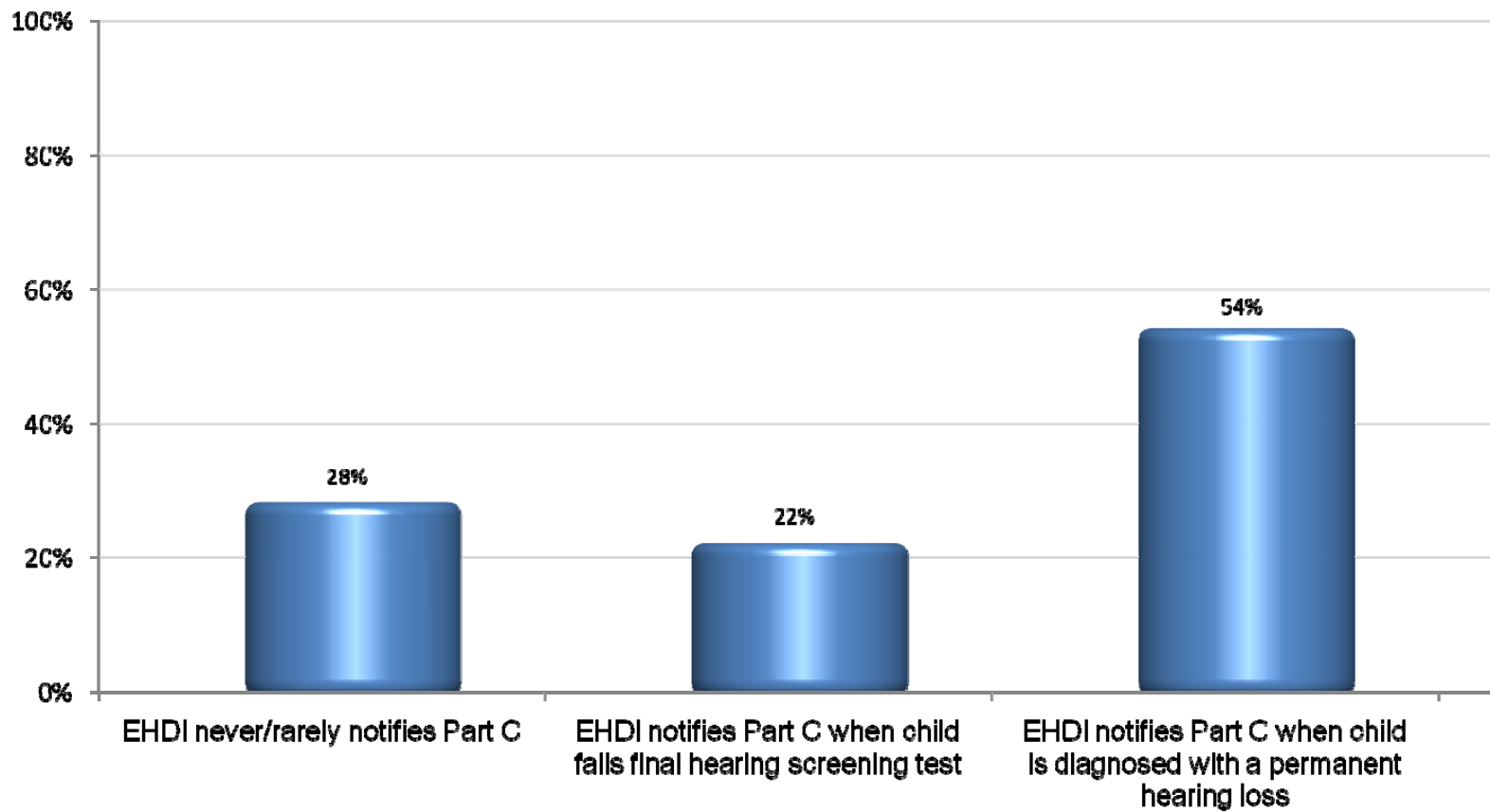
# How frequently are each of the following entities notified when a child is diagnosed with a hearing loss?



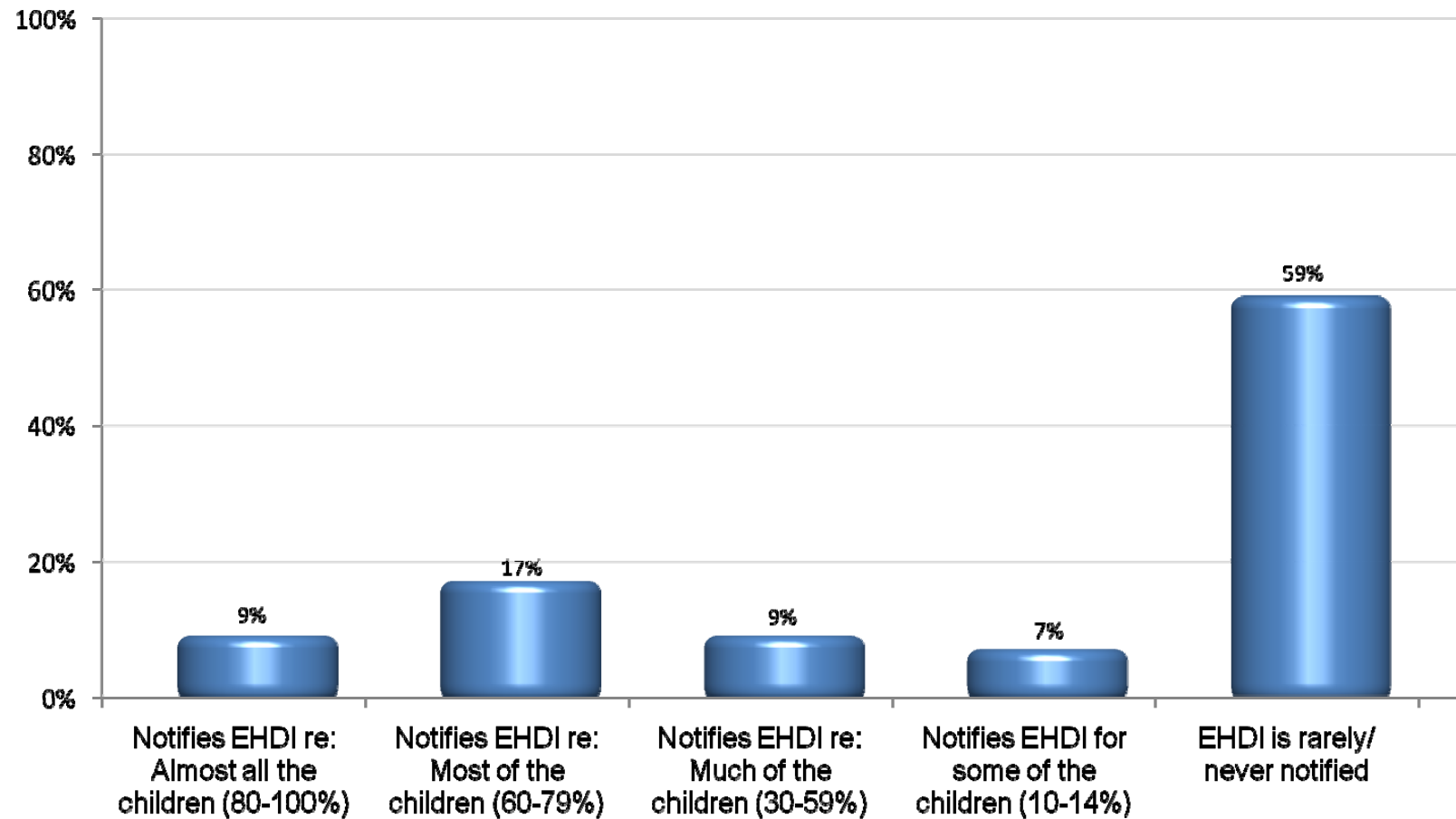
# Who notifies the baby's primary health care provider about the results of the hearing screening?



## When does the EHDI program notify Part C Early Intervention about an individual child?

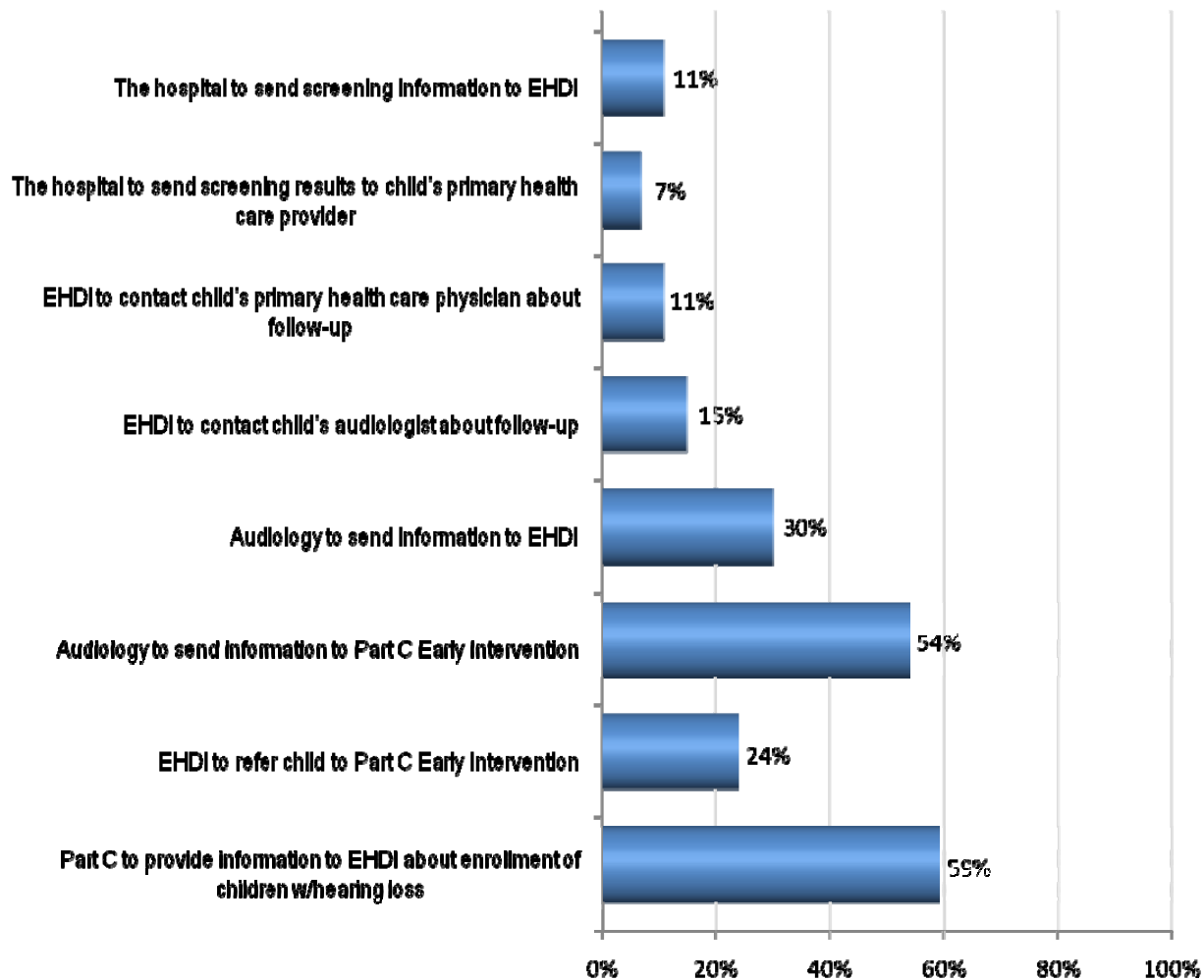


## How often does Part C Early Intervention notify EHDIs when individual children are enrolled in Part C?





## 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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