

the impact of
**HIPAA and
FERPA laws** on EHDI
programs:
Results of a national
self-report survey

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Introduction

Early Hearing, Detection, and Intervention (EHDI) programs have been established in each state and territory for the purpose of implementing and improving newborn hearing screening, follow up, and connection to early intervention services. Providing efficient EHDI services requires the exchange of information among hospitals, audiologists, physicians, and Part C Early Intervention programs. Federal privacy regulations, specifically the Health Insurance Portability and Accountability Act (HIPAA) and the Federal Education Rights and Privacy Act (FERPA), impact this exchange of information.

The Maternal and Child Health Bureau asked the National Center for Hearing Assessment and Management (NCHAM) to conduct a survey of state and territory EHDI programs to ascertain their perceptions about the extent to which HIPAA and FERPA affect the ability of EHDI programs to create and operate an effective system of services and ensure that infants and young children with hearing loss are receiving timely and appropriate services. This report provides a summary of a written survey administered to state and territory EHDI program coordinators. The purpose of the survey was to (a) determine the perceived impact of HIPAA and FERPA on the ability of EHDI programs to ensure children at-risk for hearing loss receive the needed diagnostic and intervention services, and (b) identify potential strategies employed by states to facilitate the exchange of information.

A written self-report survey was piloted, revised, and distributed to all state and territory EHDI coordinators. Respondents had the option of responding via fax, email, regular mail, or online. A total of 47 states and 3 territories responded. The survey results are presented here in relation to each of the survey questions.

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Survey Question Number One

Explain how HIPAA and/or FERPA regulations have affected EHDI’s ability to provide effective services and what you have done to address any barriers.

In general, most respondents said that HIPAA was not such of a stumbling block, often due to state mandates requiring the reporting of newborn hearing screening data as well as EHDI’s authority in monitoring this public health condition.

FERPA regulations are a greater barrier to providing effective EHDI services. Almost all state EHDI programs reported that because of FERPA they are required to obtain signed consent is required in accordance with FERPA to obtain enrollment and/or service information from Part C. Although the vast majority of states reported that signed releases of information are needed for Part C to provide EHDI with child-specific information, many state EHDI programs receive aggregate data about the number of children with hearing loss enrolled in Part C. Many EHDI respondents said that their location within the same department as Part C (often the Department of Health) facilitates communication.

Specific Barriers Noted by Respondents

- One third of respondents described some problems with HIPAA, primarily due to hospitals and private providers not understanding state-mandated reporting requirements; obtaining timely data also was cited as problematic in a few states.
- Obtaining data on “border babies,” i.e., babies born and/or receiving diagnostics in a neighboring state, are often lost to follow up. This was attributed to differing state regulations and/or lack of standardized interstate data exchange procedures.

- Obtaining diagnostic results from Education-affiliated audiologists is a barrier because these audiologists view the information as falling under FERPA.
- Forty percent of the respondents elaborated on problems associated with FERPA. Although most states reported that they can make referrals to Part C without signed consent, many EHDI programs do not get information from Part C (see Question 10 for more information).
- About 6% of the state EHDI respondents said that their program’s responsibility ends with the monitoring of diagnostic follow up; they don’t view communication with EI as relevant to their role.

Specific Strategies to Support Obtaining Comprehensive Information

- About 10% states mentioned that state legal counsel or department authority provided statements on the role of EHDI as a public health authority, providing legal backup for the exchange of information.
- Six states mentioned data sharing agreements have been signed or are being developed among various providers and agencies, delineating information to be shared and procedures for obtaining consent.
- Seven states described interagency/provider data bases that have been or are being developed.
- Six states have or are developing standardized referral forms and/or procedures.
- Three states made reference to the Title V CSHCN program—of which EHDI is a part—as also being considered a Part C provider, facilitating the exchange of information.

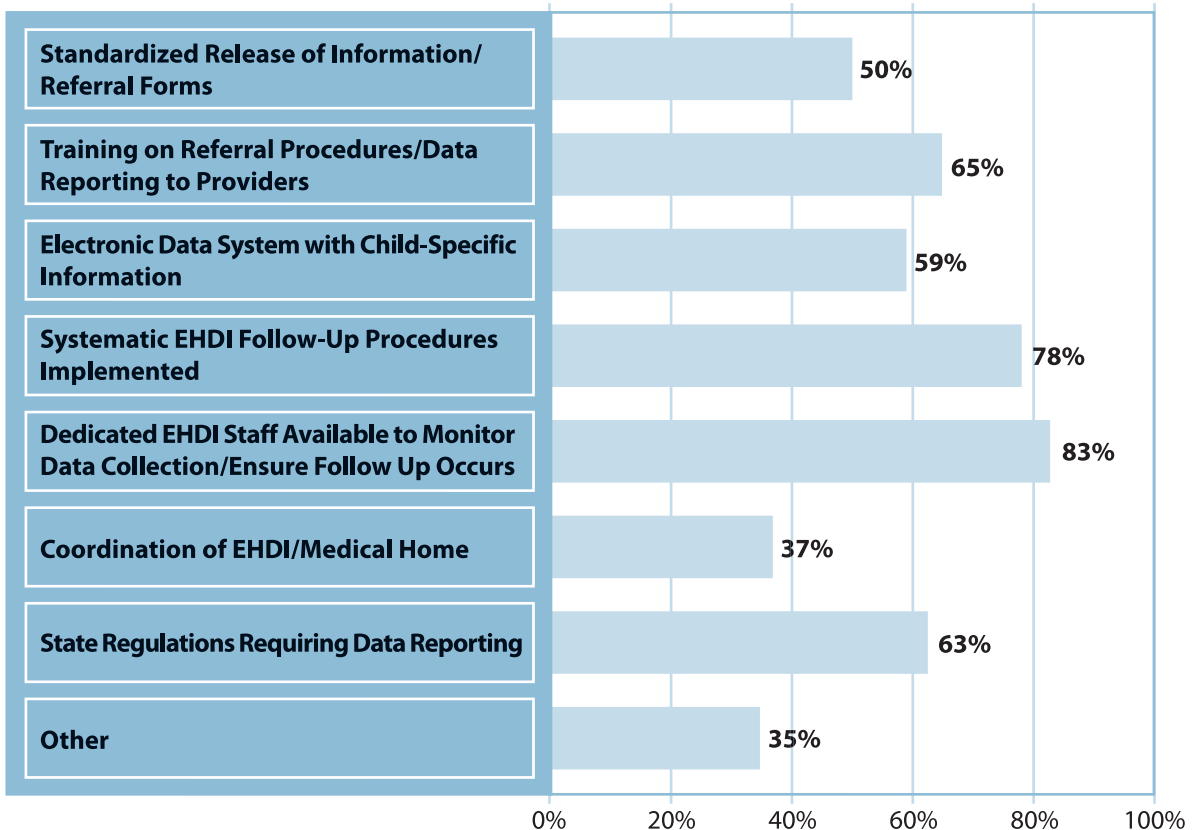
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Survey Question Number Two

What strategies are used to facilitate the exchange of information and to help connect children to needed services?

The use of dedicated staff to monitor data collection was the most prevalent strategy used to obtain needed data and ensure connection to needed services, followed by the use of systematic procedures to reduce loss to follow up. More than half of the states have an electronic data system that contains child-specific information, such as screening, follow-up testing, and sometimes early intervention data. The majority of states also provide periodic training on referral procedures and data reporting for those

providers of screening, diagnostic testing, and early intervention. Although 63% said they have regulations requiring data reporting, only 50% reported using standardized forms for referrals/release of information. Slightly more than one third of respondents reported that EHDI efforts were an important focus of state medical home initiatives. Other strategies described by respondents included data use agreements with other entities, internet-based hospital reporting, and an electronic process to facilitate Early Intervention referrals.



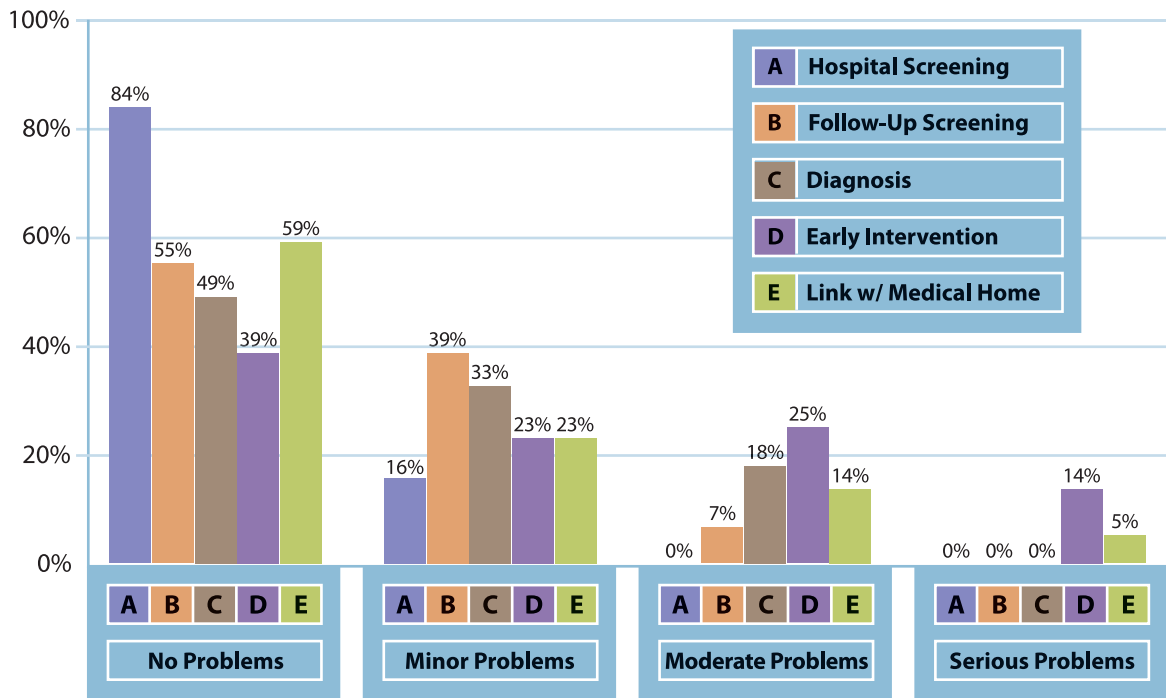
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Survey Question Number Three

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

With regard to HIPAA, states reported that obtaining hospital screening data posed minor to no problems, and only a small number of states reported moderate problems with obtaining follow up screening information. More problems were reported in obtaining needed diagnostic information, and the

majority of respondents reported minor to serious problems in obtaining early intervention data due to perceived problems with HIPAA. The degree of problems in linking EHDI with the medical home varied, with about 41% reporting that HIPAA caused some problems ranging from minor to serious.



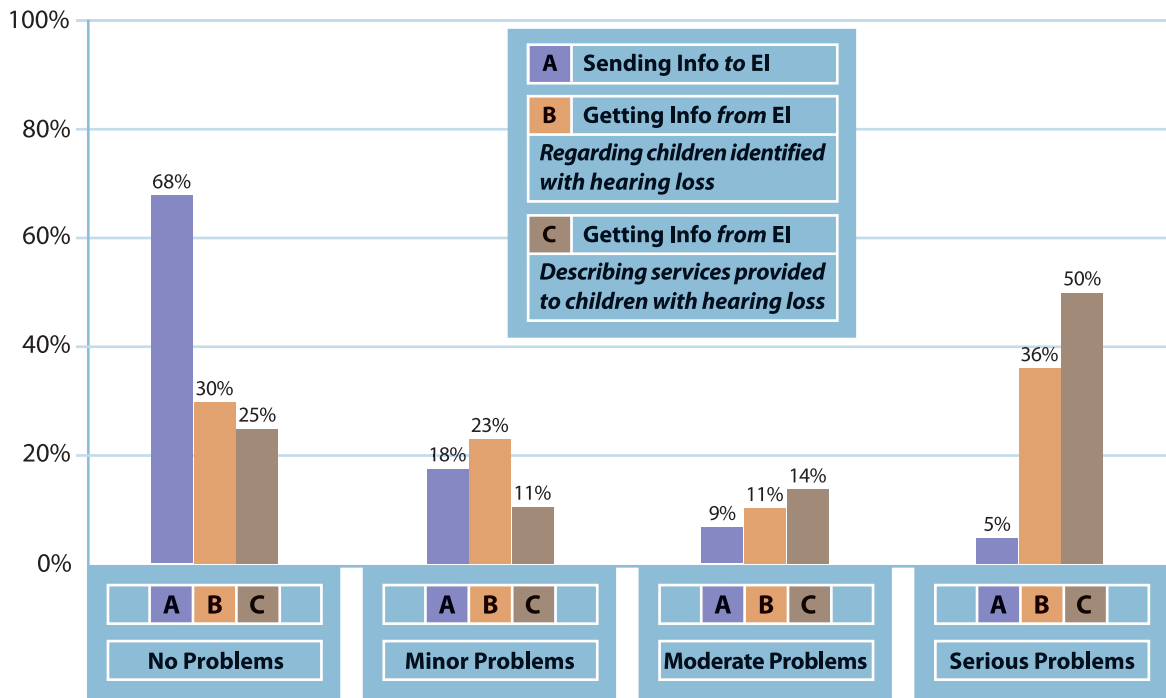
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Survey Question Number Four

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

Although the majority of respondents reported no problems sending information to EI, about one third reported that FERPA created minor to serious problems in this area. Getting information from EI regarding those children identified with hearing loss posed a problem for about 70% of the respondents, with many

reporting it as serious. Getting information from EI describing the services being provided to the children was even more problematic, with half of the states reporting that FERPA regulations had created a serious lack of information.



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Survey Question Number Five

Does your state have any legislation, memoranda of agreement, and/or policies in place that make compliance with HIPAA or FERPA easier? Fix margin.

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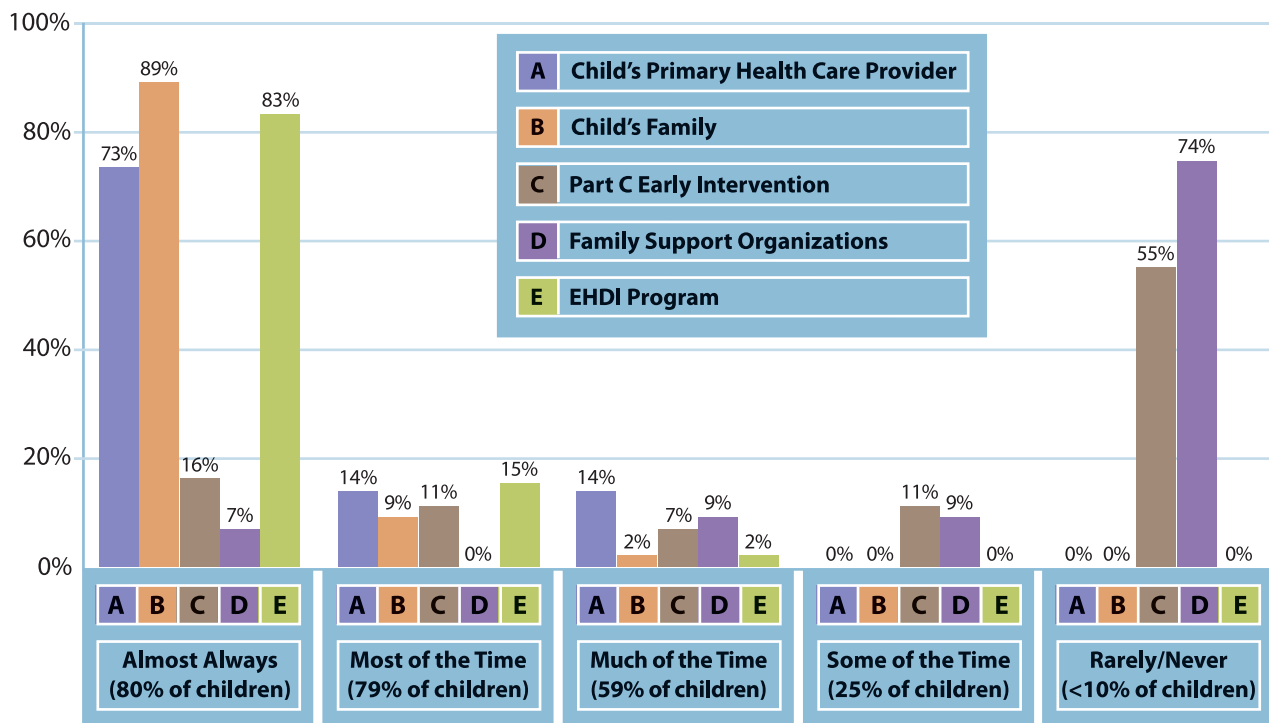
Survey Question Number Six

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

Approximately 65% of the respondents reported that they do have regulations or policies in place to facilitate compliance with HIPAA and FERPA. As described in Question #1, state legislation typically required the performance and/or reporting of newborn hearing screening. This legislation also facilitated the reporting of diagnostic evaluations to EHDI without the necessity of obtaining signed parental consent. Interagency agreements were sited in facilitating compliance with FERPA, with wording that described the information and procedures for EHDI and Part C sharing information.

The majority of states reported that the child’s family, the EHDI program, and the child’s primary health care provider are almost always notified when a child fails their final hearing screening. Notification of Part C varied greatly, with slightly more than half of the states reporting that Part C Early Intervention was rarely or never notified to 16% reporting that Part C was almost always

notified. Family Support Organizations were rarely or never notified when a child fails hearing screening by 74% of the states, with a few states reporting that family support organizations were notified some of the time to almost always. Other entities notified when a child fails the final hearing screening include the Title V CSHEN program, audiologists, and regional infant hearing programs.

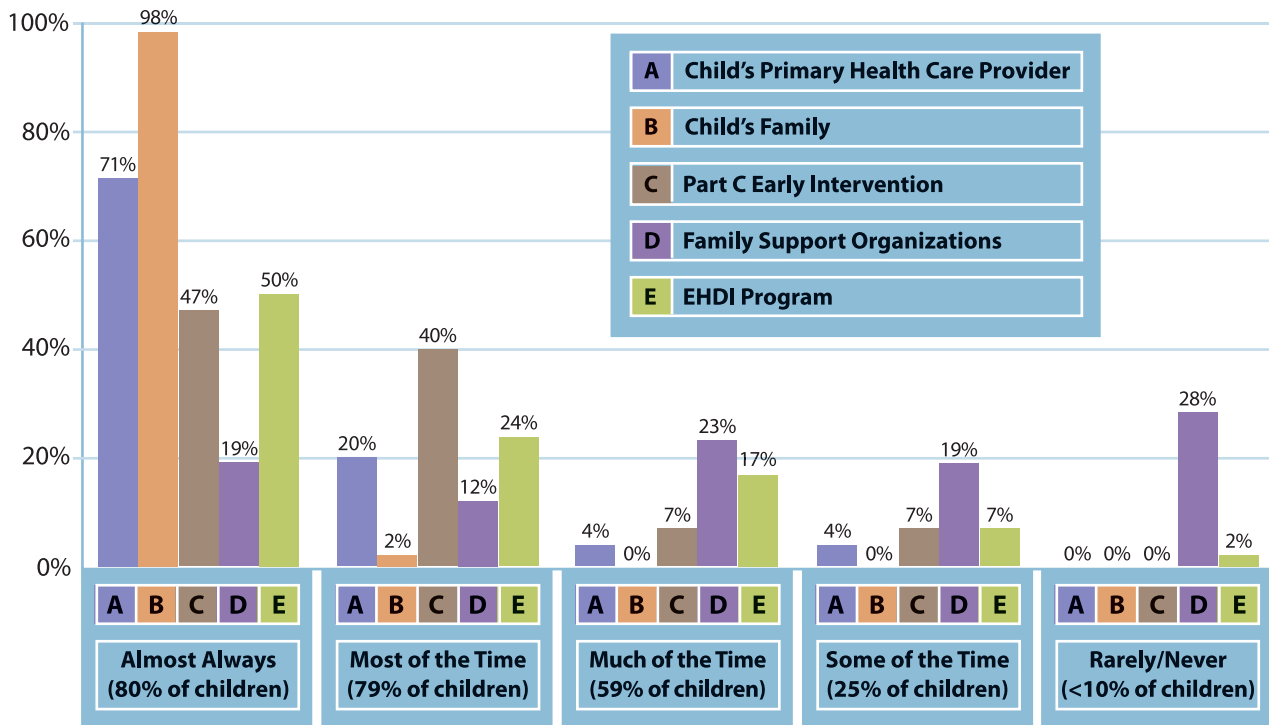


7 Survey Question Number Seven

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

There was great variability in the degree to which various entities were notified upon confirmed diagnosis of a hearing loss. The child's family is almost always notified, and 71% reported that the child's primary health care provider was almost always notified. About half of the respondents reported that the

EHDI program and Part C are almost always identified, with only 19% reporting that a family support organization is almost always notified. Other entities that are notified when a child is diagnosed with a hearing loss are the Title V CSHCN program, regional genetics clinics, and private early intervention programs.



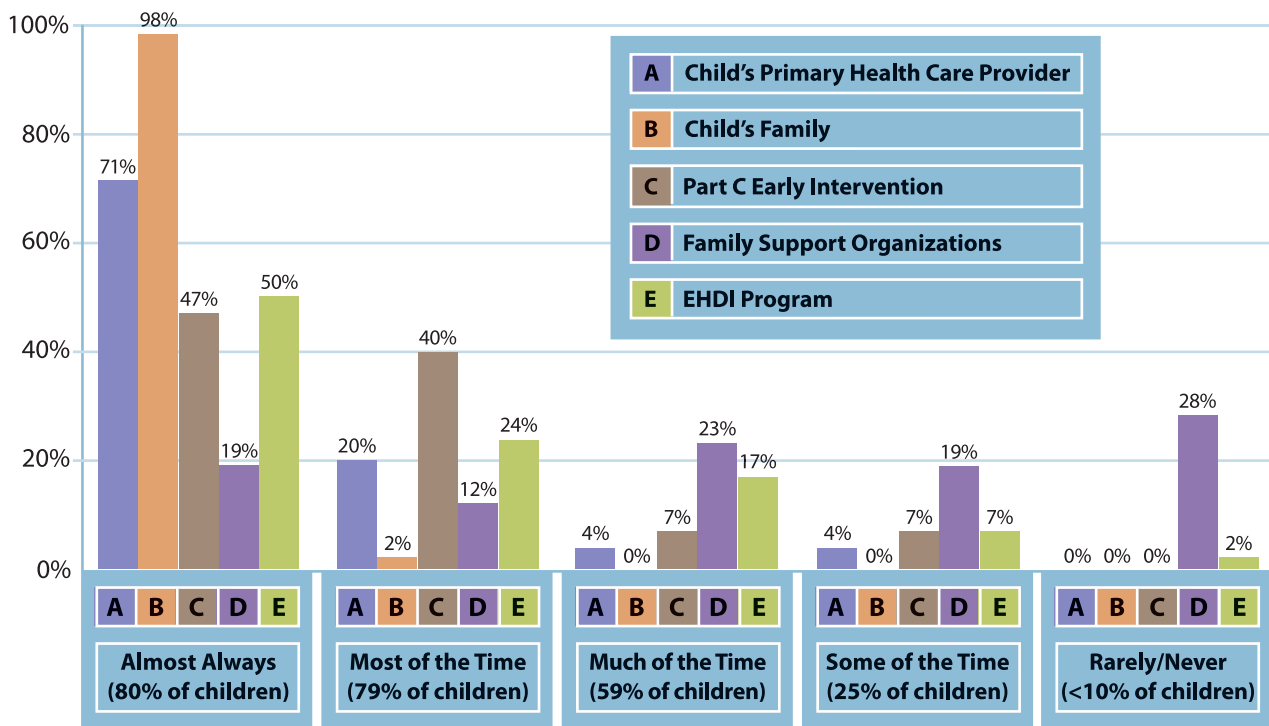
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Survey Question Number Eight

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

The results of this question point to the various entities that can be potentially impacted by HIPAA in their efforts to share the screening results with the child's medical home. Most states responded that more than one entity notifies primary health care providers and to varying degrees. Primary health care providers usually receive notification from the hospitals, followed by the EHDI program. However, these results also suggest a somewhat disorganized process for notifying primary

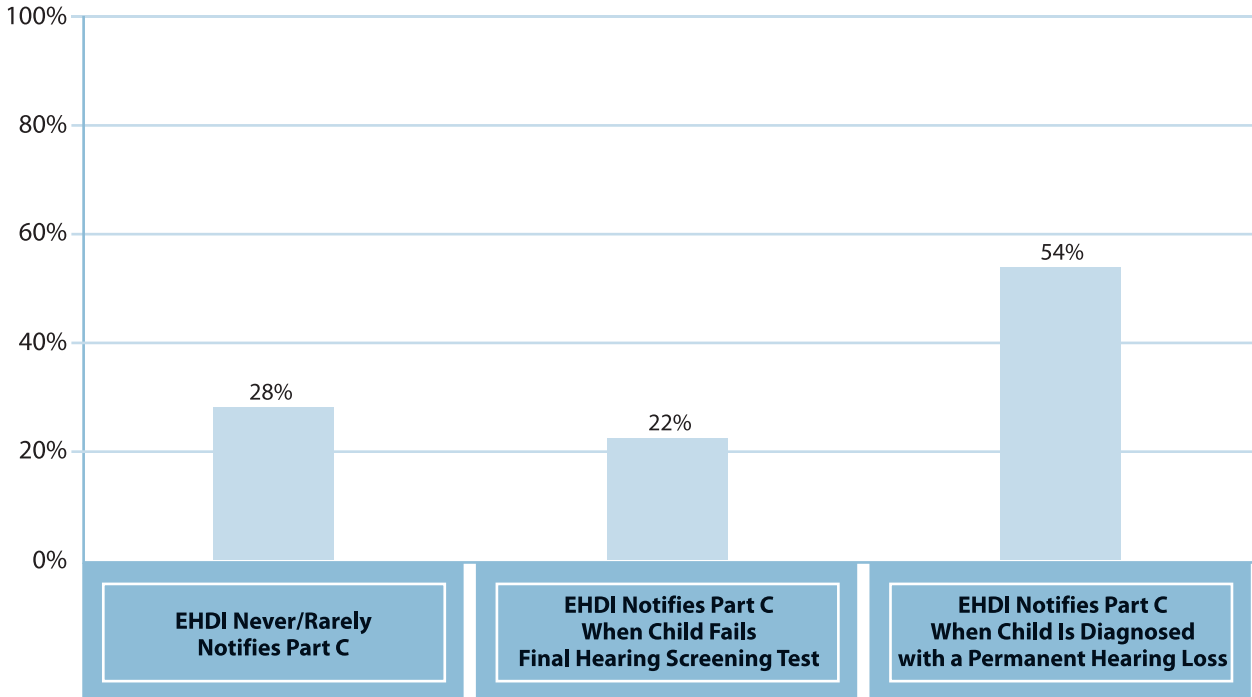
health care providers about the results of screening tests. Although hospitals do it most frequently (65% of the states report it is "almost always"), it appears that in too many cases it is left to parents to notify their health care provider. Others who reportedly notify physicians included audiologists, Part C Early Intervention, and the hospital's attending physician. One state reported that results are available to the primary care provider via an online data system.



9 **Survey Question Number Nine**
When does the EHDI program notify Part C Early Intervention about an individual child?

Surprisingly, only about half of the EHDI programs notify Part C when a child is diagnosed with a hearing loss. Neither HIPAA nor FERPA should be a barrier to this exchange of information, but it appears that it is not happening in many cases. About a quarter of the EHDI programs refer a child to Part C earlier in the process -- when the child fails the final hearing screening. It is concerning that over a quarter of the

respondents said that EHDI never or rarely notifies Part C. Follow up interviews revealed that it is often the diagnosing audiologist or regional EHDI diagnostic centers who makes the referral to Part C. Some states provide information about Part C to the families and encourage them to self refer. A few states have independent entities that provide information about an array of service options which include Part C services as well as private programs.



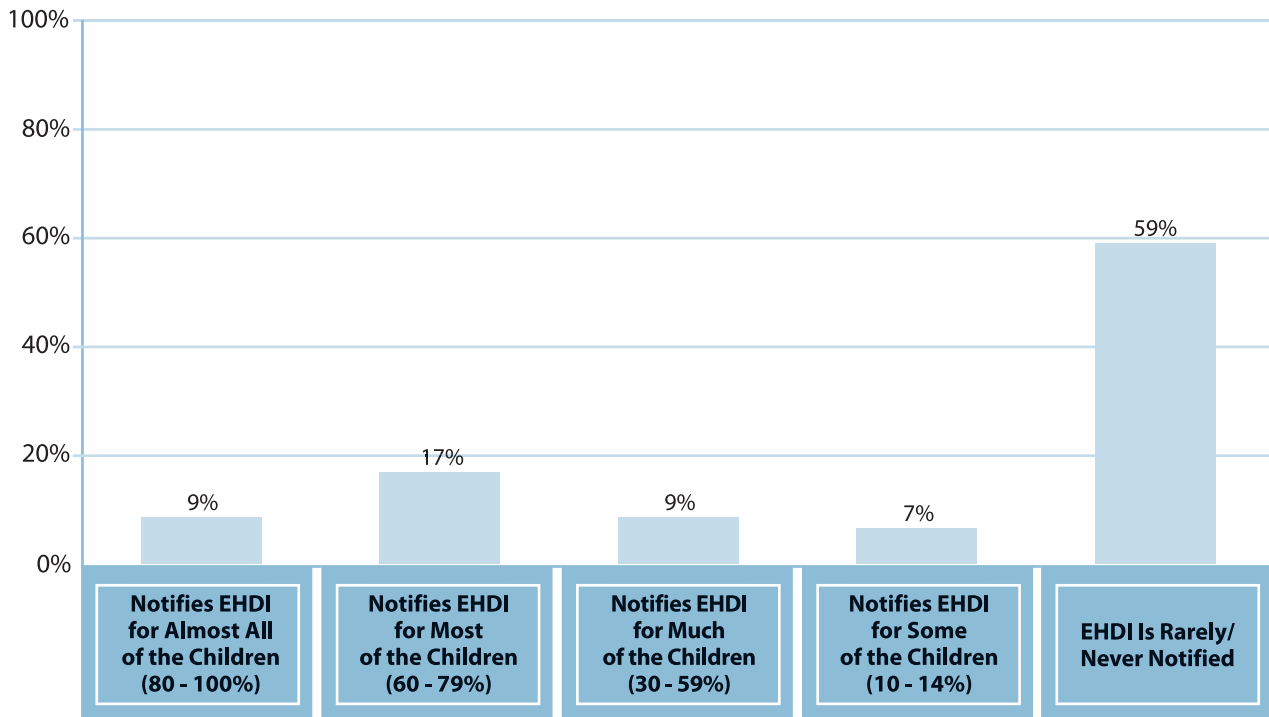
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Survey Question Number Ten

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

In general, the receipt of information from Part C at the individual child level is incomplete. Almost 60% of respondents reported that EHDI is rarely or never notified at all about the enrollment of individual children. For the remaining 40% of respondents, EHDI programs had varying degrees of success in receiving notification, with about a quarter reporting that they are notified about at least 60% of the children enrolled in

Part C. This is consistent with the responses to the earlier item about the extent to which FERPA causes problems in achieving EHDI goal to monitor the receipt of appropriate intervention. Follow up interviews resulted in some states clarifying that they do obtain information on children with hearing loss enrolled in Part C, but this is because EHDI staff initiate contacts with Part C providers to confirm enrollment.



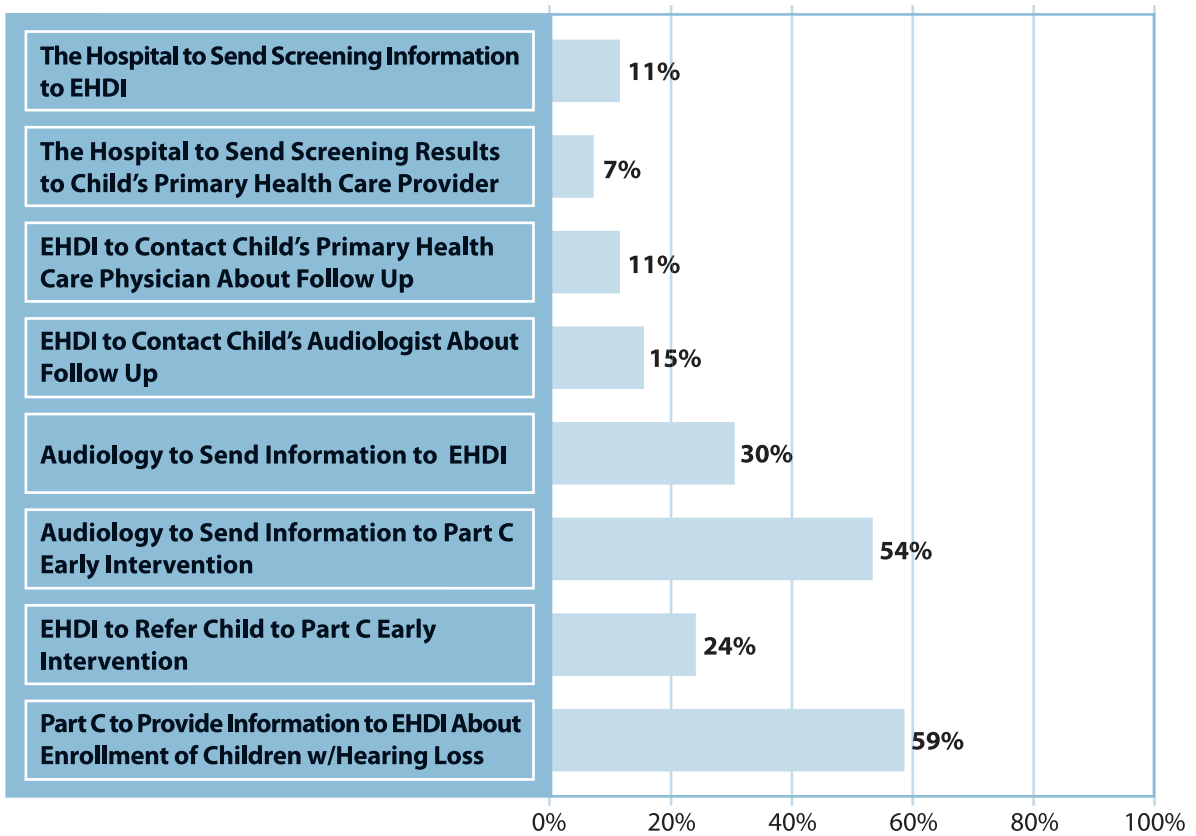
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**Survey Question
Number Eleven**

When is signed consent obtained in order for the EHDI program to share information about an individual child?

The majority of respondents reported that signed consent by parents is obtained in order for Part C to provide child-specific information to EHDI and that it is obtained by audiologists in order for them to send information to Part C. About one quarter of the states reported that signed consent is obtained for audiology to send child-specific information to EHDI and for EHDI to refer children to Part C.

A minority of states reported that they obtained signed consent in order for the exchange of screening information among EHDI, hospitals, the child’s primary health care provider, and/or audiologists. Follow up interviews revealed that a few of these states obtain signed consent out of respect for parental authority although obtaining such consent is not legally required.



Conclusion

The results from this survey reflect the perceptions that the HIPAA law causes some problems in terms of EHDI's ability to obtain comprehensive information and ensure follow up. FERPA, on the other hand, is perceived as causing a significant barrier due to the lack of data exchange with Part C Early Intervention programs. State EHDI programs that do obtain information from Part C tend to have aggregate data, which does not allow for the tracking of individual children, or the data tell them only if an individual child has been referred. Very few state EHDI programs had data regarding actual enrollment as well as information regarding services received.

In general, the linkage of families with family support organizations appears to be very weak. Few EHDI programs have data to verify that families of children with hearing loss are connected with family support entities. Only three states reported that they have Family Support entities that are contacted upon diagnosis and serve to provide families with information about the array of services available, including what Part C provides. Based on follow up interviews, other states who reported making referrals to family support said this is done by the Part C program.

Based on follow up conversations with EHDI coordinators, there was great variability in the interpretations of the federal regulations. Some states required signed consent for obtaining hearing screening and assessment data, while others did not, regardless of the presence of mandated screening and reporting. Some states and territories believed that obtaining signed informed consent was not required to obtain Part C information, particularly when Part C was housed in the same department or division as EHDI. A few states said that their state regulations requiring the monitoring of medical conditions negated the need for signed consent. Some interpreted the laws as requiring signed consent for referrals to be made to Part C while others reported that signed consent is unnecessary.

The data reflect a significant imbalance in the exchange of information with Part C, with the majority of the states rarely or never receiving information to monitor individual children. This is attributed to the difficulty in abiding by FERPA, which most state respondents said requires signed informed consent. Additionally, this lack of data appears to be due to a lack of systematic, standardized protocols and procedures to obtain signed consent in an efficient manner.

States and territories that reported the most success in obtaining data from their partners usually attributed it to strong professional relationships with frequent opportunities for communication and coordination. Some states had EHDI advisory teams or quality improvement teams of which Part C was an active member; such communication was credited as facilitating the exchange of information.

In sum, discussion, training, and technical assistance appears to be needed to help state EHDI programs in their ability to obtain needed data to achieve their mission while abiding by privacy laws. Additionally, support is needed at the federal level to develop functional regulations that can help EHDI and partners ensure children receive the needed services while protecting the privacy of families.