

the impact of
privacy
regulations How EHDI,
Part C, & Health Providers
can ensure that children &
families get needed services

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Introduction

Early Hearing, Detection, and Intervention (EHDI) programs have been established in each state and territory for the purpose of creating effective newborn hearing screening, diagnostic, follow up, and early intervention services for infants and young children with permanent hearing loss. Creating a system of effective 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), the Family Educational Rights and Privacy Act (FERPA), and Part C regulations of the Individuals with Disabilities Education Act (IDEA) which incorporates confidentiality provisions under FERPA, must be followed when such information is exchanged. EHDI programs and other system stakeholders must abide by these regulations while implementing appropriate procedures to ensure that children do not “fall through the cracks” due to misconceptions about how and what information can be exchanged.

Families of children with hearing loss are also concerned about how information is being shared and how those activities affect the effectiveness of EHDI programs. For example:

- Many families are confused by the number of consent forms they are asked to sign, often assuming that signing one form is sufficient. Instead, they are often later informed of delays because they “did not sign the right form.”
- Given the prevalence of electronic records, many families are not given copies of reports. Families do not realize that by having their own copies of reports, the family can share the reports directly with providers rather than asking the agency to do so.
- Families who live near state borders and Native American families are sometimes confused by the multiple and seemingly conflicting federal, state, and/or tribal regulatory requirements.

Note

The material in this document should not be considered legal advice from NCHAM nor from the authors. Anyone contemplating any action regarding the privacy regulations discussed herein should seek legal counsel before going forward.

- Families are not always well informed about the importance of screening follow up, diagnosis, and early intervention. As a result, families may not respond to requests for authorization, resulting in delays for services. This lack of communication and education is particularly problematic for families who do not speak English due to lack of interpreters and translators.

The purpose of this report is to provide information and guidance about privacy provisions to those who play a role in ensuring that children with or at-risk for hearing loss receive timely and appropriate diagnostic and intervention services. This includes, but is not limited to: (a) policy makers and providers of EHDI programs, (b) Part C early intervention lead agencies and service providers, (c) audiologists, (d) medical homes and other health care providers, and (e) families. The goal is to achieve more effective EHDI systems that are consistent with the federal statutes and rules that protect the privacy of individuals.

The information in this report is organized according to the various components of the EHDI system (i.e., screening, diagnosis, early intervention, the medical home, and family support). Before addressing each of these components, a summary of federal privacy laws and how they pertain to the provision of EHDI services is provided. This is followed by a discussion of how procedures that involve the exchange of information throughout these steps typically occur. Finally, “recommended practices” are offered to facilitate the exchange of information while abiding by legal requirements.

Defining Privacy Laws

The three primary privacy regulations that pertain to the exchange of information regarding infants with or at risk for hearing loss are explained in this section. Additional terms mentioned in relation to these laws are defined in the Glossary.

What Is the Health Insurance Portability and Accountability Act (HIPAA)?

HIPAA allows for covered entities, such as hospitals and audiologists, to share personal information to public health authorities such as EHDI without written prior authorization of the patient for the sake of surveillance, investigations, and interventions.

In general, HIPAA says that:

- 1 “Signed consent” must be obtained to use personal information for (a) marketing purposes, such as selling lists of patients to third parties, and (b) research.

Note

Each law uses different terms to refer to such information (e.g., protected health information, personally identifiable information). Notwithstanding that these terms have specific legal definitions, for the sake of readability, the term “personal information” will be used throughout this report to refer to all such terms.

Passed in 1996, Title I of HIPAA establishes conditions for protected health information use and disclosure by those who are required to abide by the HIPAA provisions, referred to in HIPAA as “covered entities.” It is under Title II that the HIPAA Privacy Rule was officially declared, impacting how the

various stakeholders involved in EHDI programs (e.g., hospital staff, health care providers, early intervention programs, etc.) are able to exchange information. In 2002, modifications to the privacy rule of HIPAA were made to ensure privacy without hindering access to health care.

Note

Various terms such as “prior written authorization” or “written informed consent” are used in federal statutes and regulations. Throughout this report, the term “signed consent” will be used to refer to such terms.

- 2 Signed consent is NOT required for health providers to exchange information with other health care providers for routine health care delivery purposes, which is defined as treatment, payment, and health care operations. One exception is the required signed consent to disclose psychotherapy notes, which may be part of a family’s treatment record.

3 HIPAA requires that patients be informed of their rights and the intention of the health care provider to share personal information with other health care providers.

4 Signed consent is NOT required for covered entities to share personal information if it is for public health purposes (such as surveillance of newborn hearing screening and follow up).

5 Providers must keep a record of any personal information that is shared with others.

6 Signed consent is NOT required if there are state laws that mandate the exchange of information, such as required reporting of newborn hearing screening to the child's primary care provider.

What is the Family Educational Rights and Privacy Act (FERPA)?

The Family Educational Rights and Privacy Act (FERPA) of 1974, also known as the Buckley Amendment, is a federal law that protects the privacy of student education records. An education agency, institution, or program that receives funds under a program from the U.S. Department of Education (which includes Part C Early Intervention Programs) must abide by the provisions of this law. FERPA specifies that students and guardians have a right to know about the information kept as a part of their educational records; in other words, content of records cannot be kept a secret. In general, "education records" cannot be shared with others unless parents give permission for such information to be shared. School nurse or other health information records on children served under IDEA are also considered "educational records" and require signed consent before it can be shared. Therefore, under FERPA, schools must obtain signed consent to provide any screening, diagnostic, or treatment information they possess to EHDI or other health providers.

In general, FERPA says that:

1 Signed consent is needed for school officials to share with EHDI or other

providers personal information from a child's educational records (e.g., transcripts, grades, services provided, etc.) as well as personally identifying information such as the child's social security number or student identification number; race, ethnicity, and/or nationality; or gender.

2 Signed consent is NOT needed to share a child's general contact information (name, address), enrollment status, dates of attendance at school, honors and awards. This information can be shared with (a) other education programs (b) media, (c) financial aid parties, (d) appropriate officials in cases of health and safety emergencies, and (e) juvenile justice systems to comply with judicial orders. However, schools must inform parents at least annually of their intent to share such information and give parents the opportunity to object to such information being shared.

3 Signed consent is NOT required when personal information is shared directly with the student or other school officials within the same institution where there is a legitimate educational interest. A legitimate educational interest may include enrollment or transfer matters, financial aid issues, or information requested by regional accrediting organizations.

4 Signed consent is NOT needed when it is necessary to protect the health or safety of the student or other person, such as circumstances of abuse or neglect.

What Are IDEA Part C Privacy Regulations?

Under Part C of the IDEA, the U.S. Department of Education provides funds to the lead agency in each State to establish a state-wide system of early intervention services for children ages birth to three years with disabilities (including developmental delays as defined by the individual state) and, at the State's option children under three who are at risk of developmental delays. The lead agency, which is designated by the Governor,

is responsible for identifying, evaluating, and making early intervention services available to infants and toddlers with disabilities. Lead agencies use a variety of administrative structures to provide early intervention services, including using their own staff, memoranda with other state agencies, using the staff of local public agencies, and contracting with private and non-profit early intervention service providers. The Part C privacy regulations incorporate the privacy protections of the IDEA Part B regulations and the protections and exceptions under FERPA.

In general, under Part C, once a child is referred to the Part C early intervention service program, a “participating agency” (which includes the lead agency, early intervention service (EIS) providers, and any other individual agency or institution that “collects, maintains, or uses personally identifiable information” as part of the Part C service system) must obtain signed consent before disclosing personal information about the child or his or her family. While Part C adopts the privacy protections under IDEA Part B and FERPA, its requirements differ slightly from FERPA in many situations. Part C privacy regulations have the following stipulations related to sharing of personal information:

1 Signed consent is needed for Part C participating agencies to share personal information with any individuals or entities that are not a part of the Part C system.

2 Part C’s confidentiality provisions do not apply until a child is referred to Part C and thus, signed consent provisions do NOT apply to EHDI or any other entity that refers a child to the Part C program. Under Part C regulations, these individuals or entities are “primary referral sources” and generally not subject to Part C’s confidentiality requirements.

3 In fact, Part C regulations expressly provide that anyone who suspects that a child under the age of three who may have or be at-risk for a disability is obligated to refer the child to Part C as part of the Child Find provisions of Part C regulations. If the primary referral source is an educational agency or institution that is subject to FERPA and thus precluded by FERPA from disclosing personal information, the IDEA Child Find provisions meet an exception under FERPA that permits the disclosure of limited child find information (e.g., the child’s name, date of birth, parent contact information, and reason for referral).

4 When obtaining signed consent, the lead agency or early intervention service provider is required to ensure that the consent is “informed.” In other words, the consent must: (1) describe the activity for which consent is sought (eg. initial evaluation or disclosure of specific records from the child’s early intervention record) (2) specifically identify the information that will be released (eg. evaluation to determine eligibility); and (3) identify to whom the record(s) shall be disclosed (eg. the EHDI program). In addition, if the consent is being obtained to share the results of an evaluation before such an evaluation has been conducted, the consent must confirm that the parent has not yet received or reviewed the evaluation report.

5 Signed consent is NOT needed for Part C to share individual child information with an individual or entity that is considered a “participating agency.”

6 Signed consent is NOT needed when disclosure of personally identifiable information is necessary to protect the health or safety of a child or other individual, such as circumstances of child abuse.

How Do HIPAA, FERPA, and Part C Privacy Regulations Affect EHDI, Part C, and Health Providers?

EHDI programs must comply with the privacy regulations as programs are implemented to ensure that children are screened for hearing loss, receive needed diagnostic evaluations, are connected with intervention and family support, and that these efforts are coordinated with the child's medical home. A summary of how these laws apply to each of these components of the EHDI process is provided in this section, followed by "Recommended Practices" designed to guide states in how to successfully work within these privacy regulations.

Sharing Information About

1 Newborn Hearing Screening (NBHS)

More than 95% of all newborns in the United States are now screened for hearing loss, and 42 states have laws mandating hearing screening for most or all newborns (National Center for Hearing Assessment and Management [NCHAM], n.d.).

For infants in the well-baby nursery, screening is usually done by a nurse, nurse's aide, or specially trained technician using otoacoustic emissions (OAE) or automated auditory brainstem response (A-ABR) equipment prior to discharge. Screening for infants admitted to the neonatal intensive care unit (NICU) is typically done using the same equipment a few days prior to discharge when the infant is medically stable. Arrangements for hearing screening of the small number of infants born outside the hospital are usually made by the newborn's attending health care provider.

To accomplish diagnostic testing for infants who do not pass the screen, information about the child and the screening result is typically given to one or more of the following, depending on the protocol used in that location:

- The child's parent or caregiver
- The child's primary health care provider

- The state EHDI program or designated agent
- An audiological testing center
- Another hospital to which the child is being sent
- The state's Part C early intervention program

Some hospitals schedule diagnostic appointments for the families prior to the infant's discharge while others provide families and/or other providers with the appropriate contact information. In these situations, the family would schedule the appointment themselves. Because hospitals and many health care providers are "covered entities" under HIPAA, this process of sharing personal information must be done in a way that is consistent with the provisions of HIPAA. Once information is shared with the Part C program, then the confidentiality provisions under IDEA Part C and FERPA also apply.

Based on a recent surveys of EHDI coordinators (Behl, Houston, & White, 2008):

- 1 Eighty-three percent of EHDI programs are almost always notified when a child fails their final hearing screening, and 73% of states say the child's primary care provider is almost always notified.
- 2 Fifty-five percent of EHDI programs rarely or never notify the Part C program about children who have failed their final hearing screening.

3 About 75% of EHDI programs reported that family support organizations are rarely or never notified.

4 The child's primary health care provider is usually notified about the patient's failed screening, although there is no consistent method for contacting the medical home—this notification may be performed by EHDI, the hospital doing the screening, or the parent.

5 In some cases, notification of the medical home does not happen because the hospital and/or EHDI program does not have information about which health care provider is actually providing services to the child.

Legal Requirements Related to Sharing Newborn Hearing Screening Information

HIPAA Under HIPAA, public health authorities can obtain personal information for public health purposes (e.g., surveillance of newborn hearing screening outcomes) without signed consent. EHDI is considered such a public health authority; therefore, EHDI programs are able to obtain personally identifiable screening information without signed consent from hospitals and other health care providers who perform the screening. Hospitals also may provide hearing screening information without signed consent to primary health providers and diagnosticians for the purpose of facilitating treatment.

FERPA Since FERPA pertains to Education entities (e.g., schools and Part C programs), it does not impact the release of hearing screening information gathered from hospitals or other health entities. However, once such information is given to the Part C program and becomes a part of the child's educational record, Part C may not share the information with entities or individuals outside the Part C system without signed consent.

Part C Regulations Part C regulations do not restrict hospitals or other entities from informing Part C, the EHDI, or other health care providers that the infant has not passed a hearing screening test. Once Part C receives

any information, screening or otherwise, Part C participating agencies may only share personal information to implement Part C if signed consent has been obtained (unless there is a specific exception, such as the health and safety exception). If the Part C lead agency or EIS provider evaluates an infant or toddler upon referral, the results of such evaluations or assessments, which include personally identifiable information, generally cannot be disclosed to a primary referral source without prior signed consent.

Recommended Practices for Sharing Newborn Hearing Screening Information

1 It is important that a child who does not pass a hearing screening test be referred for a diagnostic evaluation as quickly as possible. The hospital or pertinent

screening entity should make a referral for the needed next step for hearing assessment, either for an additional screening or for a diagnostic evaluation.

2 Given the role of families as decision makers and to ensure their full understanding of the screening procedures and results, parents should be informed of the screening results immediately after it occurs. Some programs obtain the parent's signature (which may or may not be part of a consent form) to document that the family was informed of the results and the referral plans. Hospital staff should inform parents that results of the screening test will be shared with the state EHDI program and the child's health care provider, emphasizing



Note
Throughout this document, the word "parent" is used to refer to the legal guardian or caregiver for the child even if it is not the child's biological parent.

the role of EHDI and the importance of monitoring hearing status to prevent developmental delays.

- 3** The parent should be given paper copies of the screening results and any referrals for his or her own records. None of the privacy laws (i.e., HIPAA, FERPA, or Part C) restrict the information that families are allowed to share with others about the infant's screening results or other personal information.

Note

The term "coordinated consent form" is used throughout this report to refer to a form that gives permission for multiple components of the EHDI program to share information with other components. Such a form should incorporate the necessary elements of HIPAA, FERPA, and Part C Privacy regulations (see <http://www.infanthearing.org/privacy/states.html#coord>).

- 4** To ensure that all providers receive needed information, states should develop coordinated consent forms in which parents give permission to share information with multiple providers involved in the EHDI process. Having only one form versus separate forms for each provider is less burdensome and confusing for families while expediting the referral process in general. Also, it helps to ensure that families have been informed about the referral and follow up testing process, so that they can be well-informed partners in their child's care.

- 5** Although not required by HIPAA, FERPA, or Part C, state laws or regulations that require the reporting of hearing screening

information to EHDI can be helpful in ensuring that EHDI programs are provided with comprehensive information and to reinforce the importance of ensuring children with hearing loss receive timely services.

Note

Many states not only mandate conducting NBHS, but mandate reporting as well by any entity with screening or diagnostic information (see <http://www.infanthearing.org/privacy/states.html#legislation>).

- 6** States should develop standard procedures regarding who will inform the child's primary care provider to avoid the possibility of this information "falling through the cracks." These procedures should account for the fact that it is sometimes difficult to identify the health care provider who will actually be providing services to the child.

- 7** Each state EHDI program should have a data system that includes information about the screening status of all newborns that is capable of providing access to information for appropriate EHDI stakeholders. Some states have integrated the newborn hearing screening data system with existing data management and tracking systems for vital statistics or "bloodspot screening."

Note

See examples of how other providers access data at <http://www.infanthearing.org/privacy/states.html#data>

Sharing Information About

2

Diagnostic Evaluations

For infants who do not pass the newborn hearing screening process, a referral to a pediatric audiologist should be made to confirm the child's hearing status.

A comprehensive infant diagnostic evaluation should be completed as soon as possible but no later than three months of age. The pediatric audiologist will conduct a series of evaluations (e.g., diagnostic auditory brainstem response [ABR], otoacoustic emissions [OAE], tympanometry, visual reinforcement audiometry, etc.). When a hearing loss is confirmed, a referral to a physician for a medical evaluation is needed to determine the cause of the hearing loss and to obtain medical clearance for any recommended amplification. If indicated, hearing aids should be fit within one month of diagnosis.

In some cases it is the diagnosing audiologist or regional EHDI diagnostic center which makes the referral to Part C. Some states provide information about Part C directly 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.

Based on the *Survey of EHDI Program Practices Related to Federal Privacy Regulations*:

- 1 About 70% of states report that the child's primary health care provider is "almost always notified" when a child is diagnosed with a hearing loss.
- 2 About 50% of EHDI programs are "almost always notified" when a child is diagnosed with a hearing loss.
- 3 Almost 30% of Part C programs are "rarely or never notified" when a child is diagnosed with a hearing loss.

- 4 About half of state Part C programs (53%) report that they pay for confirmatory diagnosis of a child who has failed hearing screening.

The variability in how stakeholders are informed when a child is diagnosed with a permanent hearing loss contributes to the high number of children who are "falling through the cracks." It is important that families are informed about and referred to the Part C system and that they are connected with services in an efficient manner. In most cases, it is through the Part C "door" that families of children with permanent hearing loss learn about the broad array of services available to meet their needs, including public and private services, family support, and the various communication approaches.

Legal Requirements Related to Sharing Diagnostic Information

HIPAA

Signed consent by parents is not needed under HIPAA for health providers to share diagnostic information with EHDI, since the purpose of such information sharing is to monitor a public health component. Some states have laws mandating the reporting of diagnostic information to EHDI programs, which reinforces the need to share diagnostic information with EHDI.

Note

See examples of legislation at <http://www.infanthearing.org/privacy/states.html#legislation>

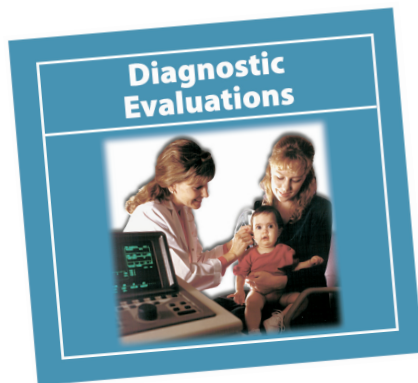
FERPA

Signed parental consent is required for a school or Part C provider to share diagnostic information that is contained in the child's educational record with any stakeholder, including EHDI. Even if a state law requires sharing of diagnostic information with EHDI, such a law would not enable agencies to share information in cases where such sharing was prohibited by federal law or regulation (such as FERPA). State laws can add additional privacy protections, but may not take away protection that is provided for in federal law or regulation.

Part C Regulations

Part C cannot share diagnostic information with nonparticipating agencies without obtaining prior signed consent from parents, unless a specific exemption applies. As emphasized earlier, no one—not EHDI, a primary care provider, or a diagnostician—needs written prior authorization to *refer* a child with a confirmed hearing loss to the Part C program.

Recommended Practices for Sharing Diagnostic Information



up” after not passing the hearing screen. However, state laws cannot remove privacy protections guaranteed by federal law or regulation, such as FERPA and Part C Privacy Regulations. Standard forms to facilitate reporting should be developed.

2 Each state should have clearly articulated policies or a memorandum of agreement between EHDI and Part C programs to ensure that any child with a diagnosed permanent hearing loss is connected to the Part C program as soon as possible. Such a referral can occur without signed consent and should

Note

See examples of Memoranda of Understanding between EHDI & Part C lead agencies at <http://www.infanthearing.org/privacy/states.html#memoranda>

1 State laws stipulating that suspected or confirmed hearing loss must be reported to the EHDI program are useful because they increase the probability that information will be shared and reduce the probability of infants being “lost to follow-

Note

See examples of standard reporting forms at <http://www.infanthearing.org/privacy/states.html#data>

be done immediately following a confirmed diagnosis if the child has not already been referred to Part C.

3 Each state should have policies and training in place to

ensure that the diagnosing audiologist always sends the diagnostic information to the child’s primary care provider in a timely, efficient manner. HIPAA does not require signed consent if the information is being shared with medical providers to facilitate treatment.

4 To ensure that relevant stakeholders receive needed diagnostic information, states should develop coordinated consent forms that authorize the exchange of information with multiple providers involved in the diagnostic process. This form could be completed at the time the child fails the newborn hearing screening test or when a permanent hearing loss is diagnosed. Having only one form versus separate forms for each provider is less burdensome and confusing for families while expediting the referral process in general. Such a form, which is compliant with HIPAA, FERPA, and Part C requirements would facilitate reciprocal sharing of information across agencies.

Note

Examples of such coordinated consent forms are available at <http://www.infanthearing.org/privacy/states.html#coor>

5 Such coordinated consent forms should be developed by a team of representatives from EHDI, Part C, as well as private and public health so that all entities are confident that the form is in agreement with their own regulations and procedures. Periodic training with providers in the use of the forms must occur.

6 Families must be well informed about the diagnostic results, the importance of intervention, and the next steps. The referral process must be explained to families and ensure they understand that information is being shared with Part C and the child’s health care provider(s). Families should always be provided with a copy of the diagnostic evaluation results and any signed consent forms. This allows the family the ability to share information with others as needed and provides back-up documentation if questions arise during the referral process.

Sharing Information About

3 Early Intervention Services

The Part C lead agency in each state is responsible for developing a statewide system of early intervention that includes, among other things, provision of a comprehensive child find system; provision of timely, comprehensive, multidisciplinary evaluation; service coordination; and direct services to children ages birth to 3 years with or at risk for disabilities, including children with hearing loss.

Each state has its own eligibility requirements which varies across states. Depending on the state, many different public and privately funded programs may qualify as Part C providers (e.g., Head Start programs, state schools for the deaf, public schools, service organizations, etc.). Each provider must comply with the relevant federal and state laws and regulations. Any child served by Part C is required to have an Individualized Family Service Plan (IFSP) that delineates all the services to be provided, including those services outside of the Part C system. The IFSP must be signed by the family and all providers, which often includes the child's medical home provider.

For EHDI programs to ensure that infants and young children with permanent hearing loss receive appropriate, comprehensive, coordinated, and timely services, it is important for EHDI program staff to know what early intervention services children with hearing loss are receiving. Because many of these services are provided through Part C, it is important for there to be close communication and sharing of information between Part C and EHDI programs (consistent with the provisions of federal law and privacy regulations).

Just as it is important for EHDI programs to refer children with or suspected of hearing loss to Part C, it is also important for Part C programs to notify EHDI about services they are providing to children with hearing loss, especially given EHDI's role in ensuring that children are receiving appropriate services.

Based on the recent Survey of EHDI Program Practices Related to Federal Privacy Regulations (Behl, Houston, & White, 2008) and a separate survey of Part C coordinators (Greer, 2008), respondents reported that:

1 Almost 60% of EHDI programs are rarely or never notified about children with hearing loss enrolled in Part C. Part C coordinators report that approximately 35% of states share IFSP information with the EHDI program regarding children with hearing loss who are enrolled in Part C.

2 For the remaining 40% of EHDI programs, data are typically incomplete and only provided for a fraction of the children served by Part C.

3 Only a handful of state EHDI programs receive more extensive data from Part C detailing the services being provided.

4 Almost half of states (47%) have interagency agreements between Part C and EHDI.

5 Over 75% of state EHDI advisory boards have a Part C representative, but only 15% of Part C state interagency coordinating councils have an EHDI representative.

Legal Requirements Related to Sharing Information about Early Intervention Services

HIPAA HIPAA requirements do not typically apply to how Part C information is shared with EHDI and/or other health providers. HIPAA does pertain to the sharing of information by other health providers who are not Part C providers or part of a program that receives funding from the U.S. Department of Education. However, such providers are allowed under HIPAA to share information for facilitating the provision of health care with EHDI or other health care providers without signed consent. Although signed consent is not needed to share treatment

information, records must be kept to document what information was shared.

FERPA Signed consent must be obtained for any education program that receives any funding from the U.S. Department of Education (this would include Part C) to share information from an individual child's educational record, including health information. However, educational programs are able under FERPA to share general contact information, enrollment status, and dates of attendance as long as parents are notified at least annually about the program's intent to share such information and a parent has an opportunity to object with respect to his or her child.

Part C Regulations Signed consent is required for a Part C program to share any personal information about children enrolled in the Part C program with anyone who is not a Part C participating provider; not even names of children enrolled in Part C can be shared without signed consent. The Part C Privacy Regulations are more restrictive than FERPA with regard to sharing information about enrollment status with nonparticipating providers. Some states (particularly those where EHDI and Part C are in the same agency) have defined EHDI programs as Part C participating providers and hence have shared enrollment information. The legality of this approach has not been tested, but the rationale for such sharing would certainly be strengthened if a memorandum of agreement exists which defines the EHDI program as a Part C participating provider. Of course, Part C can share enrollment information if there is a signed consent by the parent specifying that Part C may report specific information to the identified entities. Even if there is not signed consent for individual children, Part C may report aggregate information to EHDI, such as the number of children with hearing loss that are being served.

It is important to keep in mind that many parents choose to receive early intervention services outside of the Part C program. If these families are receiving any Part C service (e.g., coordination in conjunction with privately obtained services), they are still considered as

being served within the Part C system. Some parents (in most states this is a small minority) choose to have their children receive all of their services outside of the Part C system. If these services are received from a program that does not receive any U.S. Department of Education funds, FERPA and Part C Privacy Regulations do not apply to such non-Part C programs.

Recommended Practices for Sharing Early Intervention Information

- 1** Memoranda of Agreement (MOA) among Part C and EHDI are recommended to reflect an understanding of EHDI's role in providing services for children with hearing loss.



Note

Different terms are used— memorandum of agreement (MOA), memorandum of understanding (MOU), letter of agreement, joint powers, etc. We will use MOA throughout to refer to all such terms.

Such MOAs should specify procedures for obtaining signed consent from parents, the information that will be provided, and the time frame for submitting information to EHDI.

- 2** Part C programs should have policies and training to ensure that staff understand the importance of providing information to EHDI and to the child's medical home in a timely manner. Routine training in procedures for sending information to EHDI and the medical home along with documenting the sharing of information should be provided to local Part C programs, which typically are the ones that provide EHDI with needed information.
- 3** EHDI programs should be represented on State Interagency Coordinating Councils to foster coordination across programs and monitor interagency efforts.

4 To streamline the authorization process, states should develop coordinated consent forms that authorize the exchange of child-specific information among providers. Such universal forms should be developed by a team of representatives from EHDI, Part C, as well as private and public health so that all entities are confident that the form is

in agreement with their own regulations and procedures. Periodic training with Part C providers in the use of the forms must occur to ensure consistent use as staff change.

Note

See examples of coordinated consent forms at <http://www.infanthearing.org/privacy/states.html#coor>

5 State EHDI programs should have a data system that contains information needed to ensure that appropriate services are being provided to children with hearing loss. At minimum, such a data system should contain the date and child's age at time of enrollment, the nature of services being provided, and information about referrals to family programs.

Note

Examples of states with such systems is available at <http://www.infanthearing.org/privacy/states.html#data>

6 EHDI and Part C program administrators must be educated on the role of EHDI in helping to ensure that infants and young children with permanent hearing loss receive timely and appropriate services. Part C interagency coordinating councils should include EHDI representatives, and EHDI advisory boards should include Part C representatives. These boards and councils can play an important role in ensuring that entities are working cooperatively and that needed data are being obtained.

7 The Part C IFSP form can serve as a tool to ensure that EHDI, the child's medical home, and any other relevant providers receive information about the services being provided to the child. The IFSP form can be developed to obtain signed parental consent to share the IFSP with these stakeholders.

Note

Examples of states/programs that have developed such forms can be found at www.infanthearing.org/privacy/states.html#IFSP

8 Whether or not it is required by state or federal law (and in most cases it is required), parents should always be informed about the intent to share information about their child. Parents should clearly understand the value of disclosing this information—it allows the state EHDI program to ensure children are getting the services they need and it helps in coordinating care with various providers.

9 Parents should always be provided with a copy of the diagnostic evaluation results, treatment plans, IFSP's, and any signed consent forms. This enables the parent to provide information at will and provide back-up documentation for services the child is receiving.

10 Some states have developed MOAs among EHDI via the Department of Health and Part C whereby EHDI is considered a "participating provider" in the Part C system. Such agreements facilitate sharing of information and

coordination of services, but the legality of such agreements with regard to Part C privacy regulations and FERPA have not been tested.

Note

For examples of MOAs delineating participating providers, see <http://www.infanthearing.org/privacy/states.html#memoranda>

Sharing Information With

4

The Child's Health Care Provider or Medical Home

A "medical home" is a model for delivering primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective in a way that meets the needs of the child in the context of the family's priorities (American Academy of Pediatrics, n.d.).

For a child with hearing loss, a medical home provider can help ensure that the child's hearing screening results are known, that follow up testing is completed, and that the child receives appropriate early intervention and audiological services to meet his or her needs. Sharing EHDI information with the child's medical home provider is important, but stakeholders should recognize that many other health care providers (e.g., audiologists, ophthalmologists, geneticists, occupational therapists, speech-language pathologists, etc.) may be involved in providing services to a particular child. All such services should be coordinated with the child's medical home provider, but it is important for EHDI and Part C program coordinators to be aware of the wide range of early intervention and health care providers who need to be appropriately involved in sharing information about a particular child.

Some states have regulations requiring that a child's primary health care provider be notified of the child's hearing screening results, and in turn, that the health care provider report information to the state EHDI program regarding follow up testing. However, in some states primary health care providers do not receive or provide information consistently with EHDI programs. Furthermore, because many health care providers have a very low number of children with hearing loss on their

Note

See examples of state policies requiring reporting to physicians at <http://www.infanthearing.org/privacy/states.html#data>

patient caseload, providers are often unsure about rules for communicating with EHDI.

A Survey of EHDI Program Practices Related to Federal Privacy Regulations reported that:

- 1** In 73% of the states, the baby's primary health care provider is almost always notified about the results of a failed screening.
- 2** In 73% of the states, the baby's primary care provider is almost always notified when a child is diagnosed with a hearing loss.
- 3** In 62% of the states, hospitals almost always notify the primary health care provider about screening results; in 46% of the states, the EHDI program almost always notifies the provider, and in 39% of the states, the parents notify the provider.

With the increased implementation of medical home practices, more and more physicians are referring children for whom they have concerns to early intervention programs. However, a frustration reported by many medical home providers is not receiving follow up information from Part C about the child's enrollment status. To support the role of medical home, it is important that medical home providers and other health care providers have the information necessary to ensure all of a child's needs are met and that families are respected decision makers in identifying these needs. This includes an understanding of privacy laws impacting the exchange of information with EHDI, Part C, other health providers, and family support services.

Legal Requirements Related to Sharing Information with the Medical Home

HIPAA Signed consent is generally not needed for a health care provider to share information related to diagnoses and treatment of hearing loss with the EHDI program, since its purpose is to monitor a public health component. Also, signed consent is not needed for the medical

home provider to exchange information with an audiologist or another health care provider (e.g., ophthalmologist, geneticist, occupational therapist, etc.) if the purpose of such information sharing is to facilitate timely, appropriate treatment. Although not required by HIPAA, some states have laws or regulations

Note

See examples of state policies requiring reporting to physicians at <http://www.infanthearing.org/privacy/states.html#data>

that require the reporting of data to the child's primary care provider, which reinforces the importance of ensuring that the medical home has the needed information to provide comprehensive services.

FERPA

Signed consent is required for an educational program (including Part C) to share information with the child's medical home or other health care provider. However, educational programs are able under FERPA to share general contact information, enrollment status, and dates of attendance as long as parents are notified at least annually about the program's intent to share such information and a parent has an opportunity to object with respect to his or her child.

Part C Regulations

A health care provider does not need signed consent to refer a child with a confirmed hearing loss to the Part C program. However, Part C cannot release any information to a health care provider without the parent's signed consent. This consent must include information about the specific data to be released, the purpose, and to whom it is to be released.

Recommended Practices for Sharing Information with Health Care Providers

Child's Health Care Provider or Medical Home



1 The child's medical home provider is central to ensuring the receipt of high-quality services in a timely, coordinated manner. The medical home provider should play a fundamental role in supporting EHDI

by communicating with families the importance of screening, diagnostic evaluations, and early intervention and ensuring that these steps occur.

2 Part C programs should always consider the medical home provider as a member of the IFSP team, the medical home provider should be listed as a provider on the IFSP, and the IFSP should contain written authorization from the parent to provide a copy of the IFSP to the medical home.

3 Part C programs should consider using "eligibility status forms" for notifying the medical home provider about the outcome of a child referred to Part C. Such forms must incorporate the provisions for signed consent required under Part C Privacy Regulations.

Note

See examples of eligibility status forms at <http://www.infanthearing.org/privacy/states.html#data>

4 MOAs among state agencies, such as EHDI, Part C, and state chapters of the American Academy of Pediatrics can provide policies to enforce the inclusion of medical home providers in serving children with hearing loss, delineating procedures for exchanging information.

5 Up-to-date information regarding services and other resources for children with hearing loss and their families must be available to assist the medical home in its role of connecting families to appropriate services. Tools such as Utah's Medical Home portal (Utah's Collaborative Medical Home Project, n.d.) can ensure the medical home providers understand procedures for interacting with EHDI, Part C, family support organizations, as well as other private providers.

6 Parents should receive education about the important role of medical home providers in meeting the needs of all children, but particularly children with hearing loss. Part C, EHDI, and family support organizations can be helpful in educating health care providers about the role of the medical home in ensuring that children with hearing loss receive appropriate services.

Sharing Information With

5

Family Support Groups

Family support organizations play an important role in helping parents deal with the confusion and frustration that often comes with trying to understand the bureaucratic service system.

Family support groups are particularly important in helping families deal with the stress of adjusting to a new diagnosis, and they can offer the unique support that comes from talking with another parent who has had the same experiences.

Many such resources exist to help families of infants and young children identified with hearing loss. For example, every state has a Parent Training and Information Center (PTI; see Technical Assistance Alliance for Parent Centers, n.d.) funded by the Office of Special Education Programs in the US Department of Education, many states have Family to Family Health Information Centers funded by the Maternal and Child Health Bureau (cf., Family Voices, n.d.), and private parent support groups such as Hands & Voices (n.d.) or the Alexander Graham Bell Association for the Deaf and Hard of Hearing (n.d.) exist in many states. Such organizations provide training and information to parents of infants, toddlers, school-aged children, and young adults with hearing loss and the professionals who work with such children and their families. This assistance helps parents participate more effectively with professionals in meeting the needs of their children.

Unfortunately, many states do not have consistent, reliable mechanisms to ensure that families of infants and toddlers with hearing loss are connected with these valuable resources. According to the recent *Survey of EHDI Program Practices Related to Federal Privacy Regulations*:

1 Only about 19% of EHDI programs have procedures to notify family support

organizations about a family who has a child newly diagnosed with a hearing loss.

2 Almost 90% of Part C programs stated that they provide information to families of children with hearing loss about family support services, but most families report that such information and services are not specific to the needs of a child with permanent hearing loss.

Legal Requirements for Sharing Information with Family Support Groups

HIPAA Health care providers and EHDI cannot provide personal information with a family support group without signed consent since these groups are not considered providers of “treatment” as defined by HIPAA. However, health care providers and EHDI can provide information directly to families about various family support groups, thus allowing families to initiate contact themselves.

FERPA Family support groups that receive funding from the U.S. Department of Education cannot provide information about a specific family to EHDI, Part C, or health care providers without signed consent. Part C or EHDI programs can provide information about family support groups directly to families, allowing families to initiate contact themselves.

Part C Regulations In general, Part C programs cannot share personal information with a family support group without signed consent. However, if a family support group is a “participating Part C provider,” Part C can share personal information about a family with the family support group. Although the legality of such arrangements have not been tested, the rationale for considering a family support group to be a participating provider would be strengthened if the family support group receives a significant financial support

from the Part C program and/or if there is an MOA between the Part C program and the family support group designating the group as a participating provider. Unless they are considered to be a participating provider, family support groups must obtain signed consent from the family to share any information with Part C, health providers, or EHDI.

Recommended Practices for Sharing Information with Family Support Groups



1 An MOA among EHDI, Part C, and family support groups would help ensure that family support organizations understand the importance of providing unbiased, comprehensive information to families and

that professionals understand their responsibility of providing family groups with up-to-date information about available services. Such MOAs should also articulate the policies and practices to ensure that a family of a child with a hearing loss is connected to family support services as soon as possible.

Note

See examples from states that ensure connections to family support programs at www.infanthearing.org/family_support. North Carolina Beginnings program serves as the initial point of contact for families of a child with a confirmed hearing loss. The program explains service options and communication approaches to families and then connects them to Part C and/or private providers: <http://www.ncbegin.org>. Minnesota's Hands & Voices has a contract with the state's EHDI program whereby they are considered EHDI providers and therefore can connect with newly diagnosed families: <http://www.familysupportconnection.org>

2 Contracts or MOAs could be developed with family support organizations to make the family support organization

a part of the EHDI system and/or a participating provider in the Part C system. Such an arrangement, though not tested legally yet, greatly facilitates the sharing of information and the provision of timely services.

3 Written information on family support groups should routinely be provided to families by hospitals, at the time of a failed hearing screening, ensuring that families are connected to family support services as soon as possible.

4 Families should be encouraged to contact family support groups directly, since self-referrals do not require signed consent.

5 Permission to share information with specific family support groups should be included on coordinated consent forms referred to earlier. Families should receive a copy of this consent form, documenting that they understand that they can expect to be connected with family support resources.

Note

See examples of such forms at <http://www.infanthearing.org/privacy/states.html#coor>

6 Services from family support groups should be consistently offered as an option during annual IFSP's and 6-month updates, and relevant family support groups, at the discretion of the parent(s), should be listed as a member of the IFSP team.

7 Family support groups must recognize that they may be privy to sensitive information that the family may not want shared with other providers. Therefore, family support groups should obtain signed consent before sharing any personal information, even if the family support group is considered a member of the Part C system. An exception is in cases of known or suspected neglect, abuse, or endangerment of the child. In such cases, family support groups must report the family to police and/or social service authorities.

Conclusions and Recommendations

Although federal privacy laws have been perceived as a major stumbling block in ensuring access to services and coordination of services in EHDI programs, there are ways that providers can work efficiently within the regulations. As noted in this report, HIPAA generally does not prohibit sharing of information among health providers. Although Part C privacy regulations (which incorporate and go beyond the provisions of FERPA) require signed consent to share information with nonparticipating providers, strategies can be implemented to ensure that appropriate information gets to those who need it.

Some Key Strategies and Channels for Communicating Information

- 1** Obtaining signed parental consent to exchange any personally identifiable information should be viewed as an important method for ensuring that families have been informed about the importance of screening, diagnostics, and intervention and that they have the information needed about referrals to ensure that providers and the system respond in a timely manner.
- 2** Coordinated consent forms that incorporate the elements required by HIPAA, FERPA, and Part C Privacy Regulations should be developed to streamline the referral process and simplify often cumbersome paperwork.
- 3** Memoranda of agreements that designate EHDI programs as participating agencies of the Part C system should be considered in those cases where EHDI is serving functions beyond being a primary referral source for child-find activities (e.g., diagnostic procedures as part of the multi-disciplinary evaluations, public awareness, provision of direct services, etc.)
- 4** Memoranda of agreements among EHDI, Part C, and other relevant providers should be developed, delineating the approval of coordinated consent forms by all parties and encouraging their use to ensure timely treatment and comprehensive, accurate monitoring of services surveillance.
- 5** Families should always be given copies of diagnostic evaluation results, treatment plans, IFSPs, and any signed consent forms. This enables the parent to provide information at will and provide back-up documentation for services the child is receiving.
- 6** Although not required under HIPAA, FERPA, or Part C Privacy Regulations, state laws that mandate the reporting of screening, diagnostic, and early intervention service information to EHDI programs and to the child's medical home provider are a useful tool to encourage sharing of appropriate information. Standard reporting forms and procedures and periodic training will help reporting to be more efficient.
- 7** Although signed consent may not be required for the exchange of treatment information among health care providers, providers should ensure that families are informed about plans to release information. Providers must keep a record documenting the sharing of information.
- 8** The IFSP should be designed to include parent permission for the document to be shared with EHDI and relevant health care and other providers. This will enable EHDI to better monitor and improve services and the medical home provider to serve a supporting role in the child's overall care.

9 Policies to ensure that information about family support and resource groups is given to families as early and as frequently as possible should be developed, emphasizing the responsibilities of hospitals, EHDI, medical homes, audiologists, and Part C in providing this information.

10 EHDI, Part C, health providers, and family advocacy groups should all be included as members of coordinating groups such as the State Interagency Coordinating Councils and EHDI advisory boards.

Note

State-specific examples referred to in this report as well as the citations referenced here can be found at the NCHAM website: <http://www.infanthearing.org/privacy/index.html>

Glossary

Coordinated Consent Form

This refers to a form that provides for the sharing of information across multiple agencies and/or providers via obtaining parental informed signed consent on one form. A checklist delineating the specific entities that can exchange information is typically provided on the form.

Covered Entity

A covered entity is a health plan, clearinghouse, or health care provider who transmits any health information in electronic form.

EHDI

Early Hearing, Detection, and Intervention programs are established in each state to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. An early hearing detection and intervention (EHDI) program should comprise three basic components—newborn hearing screening, audiological diagnosis, and early intervention.

EHDI Stakeholders

This refers to those providers and agencies, both public and private, who play a key role in ensuring the provision of comprehensive screening, diagnostic services, early intervention services, and family support for children with suspected/confirmed hearing loss and their families. Such stakeholders include hospitals, pediatricians, early interventionists, audiologists, and family advocacy groups.

FERPA

The Family Education Rights and Privacy Act (FERPA) of 1974, also known as the Buckley Amendment, is a federal law that protects the privacy of student education records.

HIPAA

The Health Insurance Portability and Accountability Act is the law that ensures health insurance coverage for workers and their families if they should change or lose jobs. HIPAA is administered by the U.S. Department of Health and Human Services. Title II of HIPAA includes the “Privacy Rule” and is designed to protect the privacy of individually identifiable health information—referred to in the law as “*protected health information (PHI)*.”

IFSP

An Individualized Family Support Plan is a document developed by the Part C early intervention program in partnership with the family and other providers. It reflects the services to be provided to the child and family under the Part C service system.

Medical Home Provider

This refers to the child’s primary care provider, typically a pediatrician, who ensures that the needs of the whole child by providing family-centered, comprehensive, coordinated, and continuous care. The medical home plays an important role in ensuring that follow up to hearing screening has occurred (if needed) and that appropriate services are being provided.

Office of Civil Rights (OCR)

This Federal office with Health and Human Services, is delegated the authority to enforce HIPAA and provided technical assistance in understanding the law.

Part C Regulations

Under Part C of the IDEA, the U.S. Department of Education provides funds to the lead agency in each State to establish a statewide system of early intervention services for children ages birth to 3 years with disabilities (including developmental delays as defined by the individual state) and, at the State's option children under three who are at risk of developmental delays. The Part C regulations specify the rules about how Part C of IDEA is to be followed.

Part C Lead Agency

This is the agency responsible for the state Part C program. The lead agency may contract with other agencies to provide direct services and/or coordination services. Examples of Part C lead agencies include a state's Department of Health, Department of Education, or Department of Developmental Disabilities.

Participating Agency

Within the Part C regulations (Section 303.403C), communication among Part C providers or Part C service agencies is allowed without signed consent for the sake of serving the target child. However, such an agency or provider must comply with all Part C regulations in order to be considered a "participating agency."

Primary Referral Source

Under Part C regulations (303.221), agencies and/or individuals who are in a position to refer children to Part C are obligated to contact the Part C lead agency if they consider the child to potentially be eligible for Part C Early Intervention services, and signed consent is not required. The Child Find information that can be shared with Part C without signed consent is the child name, date of birth, and sufficient contact information to allow for Part C entity to contact the parent or guardian.

Protected Health Information

This is the term used in HIPAA to refer to information that requires signed informed consent in order to share with other providers. Universal Newborn Hearing Screening information collected by hospitals is considered public health information and not protected health information.

Signed Consent

In general, signed consent from the patient is required in order to share protected health information (under HIPAA) or personally identifiable information under Part C privacy regulations. Each law has some exceptions. For example, HIPAA allows sharing of information for public health purposes such as data necessary to ensure newborn hearing screening and follow up.

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