

MCHB/NHS September 22, 2006 Webcast

How HIPAA and EHCI Affect the Provision of EHCI Services

KARL WHITE: Welcome, everyone. We're looking forward to this web conference that will be presented by Kala Surprenant from the Department of education on how HIPAA and FERPA related to EHCI programs. Kala will present first and then there will be an opportunity during that presentation for you to ask questions by typing them into the Internet. At the ends the lines will be opened up to ask questions and have some interaction. During the first part of the presentation your phone line will be muted so that we won't have background noise on it.

Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentation. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window. We encourage you to ask speakers questions at any time during the presentation. Simply type your question in on the white message window on the right of the interface, select question to speaker from the dropdown menu and hit send. Please include your state or organization in your message so that we will know where you are participating from. The questions will be relayed onto the speakers periodically throughout the broadcast. If we don't have the opportunity to respond to your question during the broadcast, we'll email you afterwards. Again we encourage you to submit questions at any time during the broadcast.

On the left of the interface is the video window. You can adjust the volume of the audio using the volume control slider which you can access by clicking on the loudspeaker icon. Those of you who selected accessibility features when you registered will see text captioning underneath the video window. At the end of the broadcast the interface will close automatically and have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your responses will help us to plan future broadcasts in this series and improve our technical support.

So we'll now turn the time over to Kala. There were some background documents that Kala will refer to during her presentation that were distributed in the last email and those will be posted on the website afterwards. We hope you have access to them now as well. Kala.

KALA SURPRENANT: Thanks, Karl. Good morning or good afternoon, depending on where you are. My name is Kala Surprenant an attorney at the Office of General Counsel for the U.S. Department of education. Part C is the early intervention program funded through the individuals with Disabilities Education Act through which the federal government provides funds to state for early intervention programs to assist children with disabilities, infants and toddlers under the age of three and their families. In addressing their developmental needs. Many of the participants on the call may be Part C coordinators as well as early hearing detection and intervention programs and the issues today that I'll talk about are the confidentiality disclosure, records maintenance and destruction issues primarily under Part C but also as it would apply to the EHDI programs.

Next slide. As Karl mentioned, there are handouts which are available or were emailed directly to you through Karl and if you haven't received those, you're welcome to email Karl. They include an outline of confidentiality-related requirements which is perhaps like a nine-page document and has a chart that identifies the confidentiality requirements under Part C. Idea and compares them to HIPAA. That's one handout. The second are the IDEA Part C confidentiality regulations cited in the slide that you are looking at currently and two letters issued by OSEP in February of 2004. Which you'll take about during the presentation.

Next slide. So the first topic I'll talk about is the primary topic of discussion today which has to do with confidentiality and when programs may disclose information under Part C of IDEA and I wanted to talk about it in terms of three different points in time.

Next slide. The first piece that I'm going to talk about is when is parent consent required and is it required before a child is referred to Part C by what we refer to in Part C as a primary referral source, which can include an EHDI program or the State Department of Health.

Next slide. So before a child is referred to Part C, a primary referral source such as an EHDI program may be a covered entity that would be subject to HIPAA and thus would not be allowed to disclose protected health information without written authorization of the individual. And for obviously an infant for toddler with a disability that would be the parent.

PHI is defined as individually identifiable health information transmitted by electronic media, or transmitted or maintained in any form of media but it specifically includes in that regulatory definition individually identifiable health information that is protected by the family rights and privacy act or FERPA as well as records described in the site below which is part of FERPA. This provision is key in determining which confidentiality provisions may apply to programs. I've identified in the chart in the outline entitled early childhood records which you don't need to look at at the moment but I will be summarizing some of the information in it, states have determined already that either they're subject to HIPAA because they're a covered entity or they're not.

By contrast, under Part C. IDEA the lead agency, which is the agency that receives funds from Part C and any of its subcontractors or public agencies providing early intervention services must comply with the confidentiality provisions in Part C of the IDEA. Those confidentiality provisions are reflected in the Part C regulations at 303, 402.460 and those provisions reference the part B confidentiality provisions that were in effect until the part B regulations were finalized this year on August 14th, 2006. As many of you know under Part C. IDEA, Congress made amendments in 2004 which requires changes in certain areas but the confidentiality provisions were not changed dramatically. They were not changed at all. Those provisions in the statute are reflected section 617 of IDEA which applies to section 642. The current Part C regulations that haven't been yet updated to reflect the 2004 amendments still refer to the Part B confidentiality regulations and still cross reference those that were in place prior to August 14th, 2006. So I will refer to some

of the sites in the part B regs. that they refer to. When I refer to them I'm referring to the numbers of the regulations before they were revised. On August 14th under Part B.

Next slide. It's important to identify first whether you're subject to the confidentiality provisions under Part C which include not only the part B regulations but also the protections of FERPA, or whether you're a covered entity subject to the confidentiality protections of HIPAA because in general, as was indicated earlier about -- when I described the definition of PHI under HIPAA, PHI excludes information that -- or records that are protected under FERPA -- by FERPA and through Part C of IDEA. However, some states have determined either because they're a lead agency in which the EHDI program or the Department of Health or other referral sources are contained within the same agency that provides early intervention services that some states have determined that they're going to comply with both. The chart that's in the attached outline -- handout will be very helpful in identifying the requirements of both and where some of the requirements differ. The question is whether parent consent or authorization required under HIPAA before referral to Part C. Under the child find mandate of IDEA, that requires disclosure of limited information and allows the lead agency to adopt parent opt-out procedures. In February of 2004 OSEP issued a letter to an anonymous parent in Maine identifying that the child find responsibilities under Part C and the requirement that primary referral sources provide limited child find information about a potentially eligible child under Part C to the lead agency in order for that lead agency to contact the parent. That includes the child's name, date of birth, the parents' name and contact information such as

the parents' name and address and telephone number. And perhaps some contact information from the referral source.

Next slide. In terms of determining whether consent or authorization is needed prior to disclosure, as I indicated, it's important to determine which confidentiality protections you fall under. And in some limited cases you may be under both but under Part C, who must comply with Part C? Basically participating agencies which include early intervention service providers. What must they do? They must obtain written parental consent before disclosing PII or personal identifiable information. Under HIPAA covered entities must obtain written authorization of the individual before disclosing PHI.

Next slide. So the key question that often arises and it arises in a variety of contexts is, can the State Department of Health refer a child to Part C from either the EHDI program directly or because the EHDI program is required to report to the State Department of Health when a child has a significant hearing impairment? Under Part C the lead agency must have a child find system that can identify children potentially eligible. And a primary referral source is required under the current Part C regulations to refer a child to Part C who may be eligible for services under Part C. That child may have developmental delays or a diagnosed condition such as deafness. Under HIPAA, there is an argument that many states have made and I believe it was implemented in the Maine letter out of region I of HHS, the agency that enforces HIPAA, that if a disclosure is mandated by law such as IDEA that written authorization may not be required for this very limited disclosure that is required under Part C. However, some states and agencies have not -- are still requiring

written authorization because the Office of civil rights within the U.S. Department of Health and social services has not taken oh position although investigation has made determinations that they're in compliance with the law if the state has written policies and procedures that are consistent with 303.321 which mandate the referral of limited child find information. As a result of that referral, however, there are a number of other disclosure or confidentiality questions that follow.

Next slide. The other questions are one, can the lead agency disclose personal identifiable information under Part C back to the Department of Health or the EHDI program without prior written parental consent under Part C of IDEA and in general the answer would be no. However, states have asked if there are other ways in which they can address this requirement. One possibility might be to obtain consent from the parent when the initial hearing screening is done either through the EHDI program or through additional information that may be collected through the Department of Health and to have a separate consent at that time that would enable DOH or the EHDI program to refer -- to provide the lead agency with more than just the child find information, but, you know, the results of the hearing screening or any other evaluations that may be available. And at that same time -- that consent would be perhaps for really -- an authorization under HIPAA and separately obtain the requisite consent under Part C and I'll talk about that later. The second question that is a common question is can the DOH or EHDI program if it's a covered entity under HIPAA disclose personal protected health information to private physicians without authorization under HIPAA. Generally the answer is no unless there is a specific exception covered under HIPAA. But again if there is contact with that family at

that original point there may be an opportunity to obtain the requisite consent or authorization.

Next slide. What happens after a child is referred to Part C? Well, the protections of IDEA and FERPA apply once a child is referred to Part C, participating agencies are not subject to the consent requirements under Part C under IDEA and FERPA until a child is referred to Part C. Once a child is referred the lead agency, as well as participating agencies such as early intervention service programs and providers must in general obtain parent consent before the disclosure of personally identifiable information unless a specific exception applies under IDEA for FERPA. Some states have interagency agreements between primary referral services and the Part C lead agency. They're very helpful to have but they do not obviate the need for meeting the IDEA consent requirements. What can the EHDH or DOH or the Part C program do to both respect the confidentiality provisions in HIPAA and IDEA while trying to create a flow of information that can better serve children and families?

There are three suggestions. Again, these are not legal requirements but rather options that may be available to your state if they really apply and if these are challenges in your state in terms of the child find referral and follow-up to the Part C program. First is to try to obtain the authorization if there is any required under HIPAA at the first point of contact. And at the same time, obtain a separate consent that the lead agency may be able to use under Part C. That consent, since it would be obtained prior to the referral, would expressly set forth the -- would meet the requirements of 303.401 and expressly set forth

the fact that the lead agency will be able to communicate back with the primary referral source and let them know the outcome of whether eligibility was determined and if so, whether or not it was developed. In order to meet the Part C consent requirements in 303.401 and 305.71 the consent needs to identify exactly what the scope of the information that is going to be disclosed back. Second suggestion here is that identifying the records, the consent provision also needs to identify the parties to whom it will be disclosed. If it says the EHDI program will obtain that information from the lead agency after referral to Part C, it also needs to specify the requirement in the FERPA regulations that apply to Part C, that that information cannot be redisclosed. That the parents are providing informed consent. Finally, third, the -- in your state you may want to consider an interagency agreement if you don't already have one that clarifies the purpose and scope of the disclosure and the relevant requirements that apply to each of the programs because there are so many exceptions both under HIPAA and FERPA. Many of which are similar but there are enough differences it may be useful for parents as well as the agencies to have a clearer understanding of what information can be disclosed and ultimately if there is some data tracking that is done either for research purposes or follow-up, that that information can be shared. Again, the existence of an interagency agreement does not negate the obligations of the lead agency to obtain parent consent but it can often be helpful in creating a more structured process of when that consent will be obtained and streamlining that with any authorization required under HIPAA.

Next slide. So is parent consent required before disclosure by the lead agency after a child is referred to Part C?

Next slide. What would the scope of the consent under Part C look like? Example one is to specifically clarify that EHDI will disclose to the Department of Health in the Part C lead agency the result of hearing screening and the Part C and have an early intervention service referral form that is very specific to the Part C program. And while Part C does not apply pre-referral, often this information is needed after referral to ensure a complete evaluation and to ensure that evaluation results aren't reduplicated. The second piece of the consent provision or perhaps a separate piece is the Part C lead agency will disclose the evaluation results and whether the child is determined eligible under Part C if the parent provides consent if the child is determined eligible. And that -- again that consent provision could be obtained as early as prior to the child's referral to Part C in order to streamline the information that can be shared but also minimize the number of times you have to go back to the parent to obtain that authorization under HIPAA or consent under Part C. While I know that most of the programs that are on the call today that are represented are primarily concerned about the referral into Part C and the comparisons between HIPAA and FERPA and particularly Part C which incorporates the protections of FERPA I wanted to share some of the requirements that apply under Part C once a child exits out of Part C. Is parent consent required before disclosure by the lead agency of personally identifiable information when a child is ready to transition out of Part C? Obviously the consent provisions is important to inform the parent that he or she has the right to decline the consent and the receipt of intervention services at any time.

Next slide. But when a child is ready to transition out of Part C the protections of IDEA still apply and the general rule is the lead agency must obtain parent consent before disclosure. If the lead agency is also the state educational agency under part B of IDEA often the consent -- the parent consent may not be required because it's the same agency. In 3/4 of our state parts B and C are administered by different agencies and the lead agency is not the state educational agency. They must obtain parental consent. Interagency agreements must meet parent consent requirements. However, there is a requirement under Part C that the lead agency must notify the LEA where the child resides if a child is potentially eligible under part B unless the state has adopted a parent opt-out procedure and the agency documents what the parent has opted out. This option was first clarified in the February 2004 OSEP letter and it reflects the requirements in IDEA section 637A-9. Because of the child find requirements both under part B and Part C, Congress has identified it's very important for states to identify and make the transition from part B to -- from Part C to Part B seamless and identify children that qualify under Part C. The reason that this is important for primary referral sources to be aware of is under the IDEA there is an overall mandate to conduct child find for children through 21 that resides with a state educational agency. The child find mandate that applies to the lead agency or infants and toddlers with disabilities under the age of three does not negate the responsibility of the state educational agency to also conduct child find. These child find mandates are deemed to be important enough to allow for limited disclosure of the same parent contact information that can be referred from primary referral sources to the Part C lead agency from the Part C lead agency to the state educational agency under part B and that includes the child's name, date of birth, parent contact information

including the parents' names, telephone number and address and the referral sources, contact information.

Next slide. Finally I want to talk about records maintenance and destruction requirements under Part C.

Next slide. Under Part C, and the early intervention record or Part C record may not be destroyed until it is no longer needed to provide early intervention services to the child. However, the word need is defined as being at least three years beyond the last date of service. This is not expressly set forth in the regulations.

Next slide. Rather, the three-year period arrives from two different sources. Certain records such as those related to payment and the audit trail of federal funds are deemed to be needed by the lead agency and its contractors for at least three years after the last date of payment. In addition, it requires a fiscal trail to be maintained as well. In addition, other child records such as the ISSP and service provision records must be kept for at least three years under the current state complaint regulations at 303.510 to 512. Beyond that three-year period the records may need to be maintained for a longer period if applicable state statutes apply in your state.

Next slide. Whatever that period is, whether it's three years or it's five years, under Part C if at that point it is determined not to be needed by the state and the state lead agency really should have retention policies that identify and is required to have retention policies

that identify what that period is for which records will be maintained and which child records will be maintained. Then after that point a parent can request destruction of the child's early intervention record. If the parent requests destruction the agency must destroy the early intervention record but still maintain a permanent record of some limited information. That permanent record that can be maintained is of the child's name and address and phone number. His or her date of birth, service provision record, what is referred to in part B is attendance record which I think Part C would really apply to say when the child received services, what period of time, and the exit data. While I don't have slides to talk about some of the differences between Part C confidentiality provisions and HIPAA's privacy rule, in the handout that is either attached or part of the webcast, or was emailed to you through Karl White, there is a chart that identifies some of the requirements of Part C of IDEA and HIPAA's privacy rule.

In general, both statutes have similar protections in that they allow for some limited disclosures, but in general have specific exceptions under which for health safety there may be -- there may be disclosures under Part C, those disclosures are identified in the FERPA regulations at 34CFR99.31 and under HIPAA the title 45 of the CFR and part 164. In addition, both statutes require or both regulations require that the -- either the covered entity or participating agency provide specifically notice, the notice that requirements are very different. Under HIPAA the notice requirements are to provide notice of the privacy practices. Under Part C they include a broader substantive notice right when the lead agency is either provider is refusing -- the provision of appropriate early intervention services as well as notice of the procedural safeguards including the confidentiality

procedures under Part C which incorporate the part B regulations and protections of FERPA. There are some slightly broader rules under HIPAA that allow covered entities to conduct disclosures if they've included that information in their notice of privacy practices. And in addition limited datasets under HIPAA may be disclosed under 45CFR164.514. Both statutes provided for the parents or individuals to have the right to review records, to inspect and review them, to request an amendment of such records and both require the entity to maintain a record of access of those third parties that have been provided access to the child's record. The maintenance requirements are more explicit in Part C at the regulations that I cited earlier under Edgar and the general education act under GEPA. And there are more explicit requirements under HIPAA with respect to safeguarding data and litigation standard and training workforce on the confidentiality provisions under HIPAA. Since much of this information is familiar to many of you, I probably went through it somewhat quickly but I wanted to make sure we allowed time for questions and also dialogue from the states as to some of the challenges they've encountered with data confidentiality, maintenance, both in terms of referring children to Part C under IDEA and as primary referral sources, if that applies. So at this point I think I will refer back to Karl, our moderator, to determine if there are questions available or if there are any requests to go through the additional handouts.

CADE MODERATOR: Okay, Kala, there are some questions from the audience. The first one is from Nancy from Michigan. And she asks regarding slide 12, I thought in the past I heard you say that FERPA is not until the child is enrolled in Part C, IE signed ISSP. You said today that provisions apply once the child is referred. Can you clarify, please?

KALA SURPRENANT: Certainly. Thanks. Nancy's question is a good one as I shuffle to find my slide at 12 to be clear. Is parent consent required for disclosure after a child is referred to Part C? The Part C confidentiality provisions -- I'm just going to read from the regulation or perhaps paraphrase it, under the Part C regulations 303.402 the rights of parents to inspect, review records, with respect to confidentiality applies to evaluations and assessments, eligibility determinations, development and implementation of IFSPs. Individual complaints dealing with a child and -- about the child or child's family. The confidentiality provisions are specifically include the evaluation documents received as well as eligibility determination documents and those would certainly be prior to the development of an IFSP. In addition, 303.460 just requires that the state adopt policies and procedures that the state lead agency will use to ensure the protection of personally identifiable information used or maintained under this part. It applies when a child is referred to Part C. The next question.

>> The next question is there are two parts. I'll start with the first part for you. Can the authorization under HIPAA and the consent under Part C be a single document or are two consent forms needed?

>> A good question. Whether they are one document or two is not really -- I guess it could be one document. The question really is does it have to meet the specific requirements for the authorization. And typically under HIPAA when you sign an authorization you're also signing the notice that many covered entities also have at the same time you sign the

notice you received that entities privacy practices and those are attached. Part C consent is defined as informed consent and so the requirements are different. They're actually defined currently in the regs. at 303.401 which requires a little more specificity than HIPAA in some ways and they're different requirements. And that includes that the parent is informed of any information for which consent is being sought and that would be potentially disclosure, agreeing in writing which is similar and that the consent describes the activity and lists the records, if any, that will be released and to whom. So that piece has to be very specific. And the parent understands the granting consent is voluntary and may be revoked at any time. Provided that the document, whether it's one or two meets the requirements under HIPAA and the consent under Part C and is clear that the authorization being provided may be for different periods in time. The Part C consent would only really trigger when a child is referred to Part C. I don't think it matters whether it's one or two documents. Sorry for the long winded answer.

>> The second part says does the Part C consent need to specify the local early intervention program? This information may not be available at the time that the EHDI program has contact with the family.

>> That is a good question and I think it depends on the nature of that local EI program. Here is why. The Part C provisions apply to participating agencies so if it's clear that the local EI program is the contractor of the Part C lead agency like a direct contractor as opposed to a subcontractor the assumption would be that the contract includes the requisite confidentiality provisions. Why does this chain matter and why it matters is that

the primary referral source is really acting as the lead agency in obtaining that consent. And then hopefully transmitting that consent document to a lead agency. Can it just say the local early intervention program? Perhaps if it can be defined more specifically such it was in a specific geographic region or a county system that would be useful. If the interagency agreement would identify the structure of the Part C program such that the EHDI document or whatever the consent form that's being signed could define that structure as well and identify it, that would be helpful because it would then provide parents with the information to be able to provide the informed consent that's required under Part C.

>> Next question.

>> The next question is from Phyllis Johnson. I'm not sure where she's located. But asks can a Part C child find agency report back to DOH if no contact is made with the family, IE, lost to follow-up?

>> Under Part C, there are certain time lines that apply. Under our current regulations within 45 days of referral a child must be evaluated and assessed and an ISSP meeting conducted. That can't be done if the referral form is incomplete. So clearly one of the pieces of information that may be needed on the referral form is the referral source and part of that is to be able to follow up and ask back do you have any other contact information? Again, you can be very careful. If you don't have parent consent under Part C really you can't ask much more than that or really disclose more than that. It's not that you

can't ask. It's usually the referral source can't tell you. But if the Part C lead agency has not had any success in contacting the parents, certainly they can contact the referral source to ask if that is, in fact, accurate parent contact information. Next question.

>> Under HIPAA, if an infant is initially screened for hearing loss by private audiologist or physician is the audiologist or physician required to obtain parent consent to send NHS results to the State Department of Health?

>> Again, I work at the U.S. Department of education and while I don't comment specifically on how HHS would administer HIPAA in this context and I can't directly comment on it, the provisions of HIPAA require physicians to not disclose that information unless it is a specifically -- it meets a specific exception under HIPAA, for example if there is public health or safety exception that would apply. And in general, I'm not sure that there is one that would apply as a general rule. There may be other specific exceptions that could be -- that could apply in specific circumstances but in general it doesn't seem there would be one that would apply but I would refer you to the HHS-OCR website which is also information included in that handout attached. Next question.

>> The next question is from Karen in Arizona and she is actually referring to the previous question. It says based upon your answer to the previous question it would be sufficient for a health provider to use a consent that only specifies the lead agency's name and not the contracted provider, is that accurate?

>> For purposes of referral to the Part C program, Part C does not apply at that point. I -- in response to the earlier question, Karen, that I believe came from -- I'm not sure who it came from. The question was raised was can the Part C consent form that's obtained pre-referral, does that need to include the local EI program and I said it would be useful to include it. But in terms of communication back to the EHDI program from a local program, the local program would need to be able to receive that information from the lead agency. The lead agency is the only entity referenced in the consent form. In many cases, that may be possible because the local program is either an authorized representative of the lead agency or is a contractor that has expressed contractual provisions that meet the requirements of 84.36l and -- includes the Part C confidentiality. It would depend on the administrative structure in the state if that information could be shared from the lead agency to the local and whether the local could send that information back to the EHDI program. It's why it's useful to have at least had an interagency discussion between the programs to determine how Part C is structured in the state. And how to best accomplish that consent and how specific it needs to be. Next question.

>> Next question is we have administrative rules in our state that require audiologists who conduct outpatient hearing evaluations to report their finding to the EHDI program. My question is to whether the state regulations require audiologists to report to take -- report take precedent over any FERPA provisions. Are the audiologists required to report without consent per rules or are they required to report without consent based on FERPA?

>> That is actually a complicated question, the reverse of what we've been talking about which is generally referral of children from EHDl programs into Part C, this is talking about the school system which may or may not involved part B of IDEA but very likely involves the family education rights and privacy act that I don't specifically review. In terms of the FERPA provisions there are some limited exceptions in 99.31 that may apply if the disclosure is required either pursuant to federal and state law or if there are state and local officials to whom such disclosure must occur. The -- I'm trying to find the 99.31 provisions. If that is a specific concern in your state I think a quick email to the family policy compliance office within the U.S. Department of education and their website is also in the handout may quickly identify the provision 99.31 that may apply to allow that disclosure to occur if it's a requirement in your state. Next question.

>> One of your slides indicates that notification to the LEA is required only for children who are potentially eligible for part B. My state has interpreted the law to require notification for all children who are transitioning from Part C. For whom is notification required?

>> That is a really good question. Actually, to clarify, your state can certainly interpret potentially eligible for part B to be as broad as all children going to Part C, that's an allowable definition. If that's how it's interpreted in your state, then those are the children for whom the LEA notification, as well as the 90-day conference would apply. There are other requirements under Part C based on how you designed children potentially eligible under part B. The statute at 637-A-9 was amended slightly that a transition conference

occur within a slightly longer window and the LEA notification provision currently both in the statute at 639 -- 637A9A as well as regulations at 34CFR148 B-1 actually required the LEA notification occur for all children. I think my slide may be somewhat inaccurate. The reporting requirements that lead agencies must conduct under the state performance plans is only for children potentially eligible under part B. I hope I haven't confused everybody. That's the response and if you have questions, feel free to follow up on that one by email to me.

>> Okay. This next question is from Sid. He asks, letter to anonymous in Maine includes specific info that hospital can include in referral of to Part C, reason for referral is not included. For example, if pediatric audiologist is employed by hospital, cannot the hospital include deaf or hard of hearing status of baby?

>> A good question, Sid, and this is actually -- that letter was issued by the Office of Special Education Programs but it was done with consultation with folks at HHS and within the department in terms of our confidentiality provisions as they are applied both in the school context under FERPA and under Part C. The determination was made that in balancing and the mandate required under IDEA in terms of child find and the privacy rights of children and families, that the identification of the reason for referral or any information that would be sort of what we would think of as medical information or diagnosis-tip information would be too far and too intrusive on confidentiality rights of parents and families. Rather, it was to at least provide the minimum contact information so the Part C program could communicate back with the parent and determine if the parent

wanted to pursue an evaluation. Provide information about the program or just say no thank you without having disclosed specific information. Of course, that information would be helpful to the Part C program and of course from C to B in terms of conducting triage and determining what records and evaluations are needed and why it's useful to have two referral forms. One if you've got the requisite authorization if that's required that would allow for that detailed information be provided. Next question.

>> That was the last question from the Internet audience. One more just came in. We'll read this one before we open the line for the telephone audience. When a DOH facility sends notification of failed newborn hearing screening to a Part C EI program to locate and assist parents in locating rescreening facilities, is the Part C facility required to obtain authorization or is it the lead agency's DOH responsibility to make sure that pre-authorization was obtained by the birthing facility? That came from Phyllis Johnson in Tennessee.

>> Maybe Phyllis could -- I had trouble following that question, I must say. I just think there were too many layers. I couldn't tell if the authorization was questioned was whether it was the authorization under HIPAA or Part C. Maybe you could read it back one more time and I'll try to capture it. Otherwise we might have to open it up.

>> I'll try reading it one more time. When a DOH facility send notification of failed newborn hearing screening to a Part C EI program to locate and assist parents in locating prescreening facilities, is the Part C facility required to obtain authorization in or is it the

lead agency's DOH responsibility to make sure that pre-authorization was obtained by the birthing facility?

>> I see. I think I see the question. Part C is never required usually unless they're a recovered entity to obtain authorization they would have to obtain consent. Is Part C required to obtain consent for the screening instrument to be transmitted to DOH to Part C? No, if it's DOH that's conducted the screening and has those results, they might need to obtain consent or the hospital or birthing facility, if that is a entity that has those records. In general under HIPAA and perhaps under other confidentiality provisions that entity is required to obtain authorization before transmitting information to Part C. However, I don't see anything in HIPAA that would preclude the Part C lead agency from executing that authorization and why I think the interagency agreement would be helpful. It is not only about getting information into Part C but even post referral in terms of accessing records. It may be useful for Part C to have the lead agency to have a structure -- an understanding of how the structure of referral occurs in the EHDI and DOH programs so that they can determine whether there are -- it's sort of one stop shopping once they see a parent if they get consent to do an evaluation they can take any requisite authorizations. Then the consents or authorization forms are required to be maintained as part of the record varies but in general because of the record of access rules being similar in both statutes, it would be prudent to keep a copy of that signed authorization in the birthing facility's record. I hope that was helpful and responsive. I hope I understood the question. That's it, I think for our questions. Is that right?

>> Well, let's see here. There is one more that just came in.

>> They're trickling in.

>> They're trickling in. This is Lu Christianson from the Hawaii newborn hearing screening program.

>> -- which has public health authority status under HIPAA and an EI program?

>> Well, it's not FERPA per se that would apply to the EI program. I think he was from Hawaii is what you said. Hawaii's lead agency is not a state educational agency but the Department of Health. They do incorporate the protections of FERPA. And the newborn hearing program may or may not be subject to HIPAA depending how it's treated as a public health entity. If there isn't a requirement to retain authorization from the newborn hearing screening side clearly that information may be able to be disclosed to the EI program particularly if they're in the same house and same agency. In terms of the EI program's ability to refer -- not even to refer but to disclose information back to the newborn hearing program within that agency, it may or may not be required. It partly depends on whether the lead agency program is defined narrowly as that EI program and also whether the newborn hearing piece of that agency is considered a participating agency t under Part C, the disclosure that occurs back may not need the prior parental consent. Of personal identifiable information under Part C. On that specific question I

would urge you to either email me directly or contact David, the Hawaii state contact because I think it's very specific to your agency and to your state. Other questions?

>> After the state newborn hearing screening program refers to Part C they ask for information about that child. Was child eligible, when did IFSP services start, etc. Can Part C release that information without a parent release?

>> In general, no. Can that -- it's not really a release it's called parent consent. But it's -- I think that's the same requirement. In general the answer is no but I made suggestions earlier about how and when the consent could be retained. When the lead agency is obtaining consent for an evaluation and then at that point also explain to the family that for whatever purposes are that they would like to be able to communicate back with the specific primary referral source and identify the program as well as identify which type of records would be disclosed. And that would have to meet the requirements in 303.401.

>> That looks like all the questions from the Internet audience. I'm going to now unmute the phone for anybody on the telephone line. I will let the people on the telephone know there are multiple people out there. Please try not to step over anybody asking a question. Here we go. Is there anyone on the telephone that would like to ask a question now?

>> The question from Washington State.

>> Go ahead, Washington

>> It might be similar to the one that was just answered but as information in Part C is collected it becomes an education record. Part of the education record. If the information is actually generated from another source like the evaluation information from an audiologist, can Part C, with parent consent, share that evaluation with another entity, or can you only share records that you generate yourself within Part C?

>> That is a good question from Washington and it wasn't actually answered yet. The question is I think two-fold in my mind as a lawyer. One is does -- do the Part C confidentiality provisions apply to sort of the entire record, the child's early intervention record, and they do apply to disclosure of any person's identifiable information in the child's early intervention record. In terms of the consent prior to disclosure, again because the Part C confidentiality provisions applied to the record and to the specifically to protect the personally identifiable information which could be an audiologist report consent would be required prior to disclosure. That consent would need to identify what was being disclosed. The fact that it was obtained from a third party would not negate that consent if it was provided appropriately under Part C by the parent. I hope that's responsive.

>> Thank you.

>> Is there anyone else on the telephone line that would like to ask a question now?

>> This is Karl White from Utah. Could you clarify what a covered entity is to make sure we all have the same understanding of that and then assuming that a stated EHDI program is located in a Department of Health and not considered a covered entity under HIPAA and if the Part C program is also located within the same division in the Department of Health, does that change any of the restrictions on sharing information since they are both actually the same agency? And they're sharing information with themselves?

>> Karl, that's a good question because I think you're following up on some comments I made out of the question from Hawaii. It may -- we don't administer this. The U.S. Department of education doesn't administer HIPAA and we can't go through the analysis of what is a covered entity. Because the privacy rule has been around for a while. You know whether you are or not. If you don't, ask your agency attorney whether your program is covered under HIPAA or not. The question you're raising is assuming you aren't covered because you're a public health entity to which the HIPAA's privacy rule does not apply because you aren't considered a covered entity as determined by the criteria that's identified on HHS's website as well as in the regulations at 45CFR part 164, then the question is if HIPAA doesn't apply, is there -- can there be some other authorization requirement potentially under other statutes? Yes, there may be some state law that applies or other confidentiality provisions. If there are not provisions that would apply to that public health entity the question is can they send information to the Part C lead agency? Part C—

>> And can they get information back.

>> It's two separate pieces. Part C would not apply until the child was referred to Part C, as to the information going from the EHDI program or the Department of Health, public health entity to Part C that would not be governed by Part C, however, the information that goes back, it's not clear to me whether it would be considered a participating agency because under the Part C regulations it is really a primary referral source, not necessarily an agency that is being used to administer Part C in the program in the traditional sense it's an early intervention service provider. When the Part C notice of proposed rule making goes out, hopefully, this year or certainly perhaps early next year the way it is, this would be an important area in which it would be useful to seek clarification if it's not provided. But I do think that because there are so many different variations on how State Department of Health agencies are run and how the Part C programs -- whether they're embedded within a program that serves many other children and families through other programs or whether they're truly discrete entities, I think it's useful to come back and ask in your states specific context if this is an issue you think could be helpful to get resolved in your state. Perhaps the consent might not be needed. I don't mean to put you off, Karl. But I'm uncomfortable answering it generically and say I don't need to get consent anymore. So I think I would probably want to have more information about that state and when there are state contacts through the Office of Special Education Programs and also you're welcome to email me and we'll put you in the loop with the right set of folks to get it answered.

>> This is Sue Brown from Hawaii. I'm also following up on Lu's question and Karl's question. I want to get more information about looking at that issue of a participating agency. Would you recommend that I email both David and you simultaneously?

>> That would be good.

>> Okay. Thank you. Any other questions?

>> This is Karl again. I have one more. Are you familiar with the heel stick test of newborns? Caller: I've had three boys. At least one of them has had it, perhaps more.

>> So virtually all children receive this heel stick screening where blood spot is collected while they're in the hospital in most states it's sent to a state agency to analyze and then the state agency turns around and if it's a positive test notifies the baby's healthcare provider of record and also the baby's parents and says we've got a positive result here and need to follow up. That seems like it's quite similar to what we want to do with newborn hearing screening when we notify physicians or early intervention providers. How do they get around these issues? Because I don't think they have parental consent to share that information back to the primary healthcare provider, maybe they do. Then maybe you just don't know, either.

>> I don't know under what authority the -- it sounds like there may be a public health exception. There is not one that I'm aware of specifically under FERPA but this is not an

area where FERPA would be triggered but there may be -- I'm just not sure if anyone knows what the authorizing authority is, either, by name or statute. I would be happy to look into it but I don't really know what authority is -- under which the health -- you know, the newborn health screening is conducted. But I imagine that there is express authority that allows us to be a public health exception. In terms of at least communicating back to the -- to the hospital and even perhaps to the physician, the care provider. You're pretty sure they don't have a consent provision. I don't even remember because after delivery you can't remember anything. You're pretty sure there isn't a consent provision up front, right?

>> Someone on the line may know. It's an opt-out the heel stick procedure happens as standard procedure unless the parent objects to it.

>> We have certain opt-out procedures under IDEA opt-out consent provisions and that may be there is a consent provision, not an affirmative consent but an opt-out. If anyone knows the authority I would be happy to look into it. There are some parallels and particularly in a state where the Department of Health is the lead agency and is administering these other programs there may be some exceptions that could apply that might be useful in a particular state.

>> This is holly in California. It's my understanding that HIPAA does not apply if you are disclosing protected health information for treatment services. So if you are -- you know, referring information about a child who needs treatment that HIPAA does not apply.

>> You think that would be the exception under which the heel stick program?

>> I mean, I would -- I don't know specifically about the heel stick program but I thought that applied sort of routinely when you make—

>> Yeah, that is true that there is an exception under HIPAA. It doesn't really apply when there is a referral to Part C because it's not seen as treatment but rather referral to a completely different program and the voluntary nature of Part C creates that demarcation.

>> It would seem like if that exception applies in the heel stick sense, holly, it would also apply not for the Part C portion but in newborn hearing screening in the same way because they're both screening procedures. They both have some false positives and false negatives. It is not a diagnostic procedure but you're referring a child on for further evaluation and treatment.

>> I'm okay with that.

>> This is Stacy from Vermont. I don't have our -- the head of our -- the head nurse from heel stick here but we've been looking at the issues in Vermont as well. My understanding is that the heel stick program is an issue of a public health aspect and hearing doesn't fall under that so that they have some -- a little bit more looseness when it comes to reporting and than we do with hearing.

>> I guess one of the questions might be then why doesn't hearing fall under it and is it possible appropriately to define hearing in that category?

>> Well, my first response would be that hearing isn't life and death and some of the heel stick testing is. That if those results are not reported and intervention doesn't take place within a certain amount of hours of life, that there could be detrimental effects on the child.

>> Some of it is life and death but the vast majority of things we refer things for from heel stick are not life and death. For example, hypothyroidism and so most children that get referred on to heel stick are not in life and death situations. Certainly there are dramatic exceptions.

>> This is Therese in Texas. I want if it has to do with the timing of our programs. That is, hearing screening programs and the legislation is substantially later than most of our heel stick programs and I know that when we've passed our law in Texas we were simply held to a different standard. And we had to say we would do different things that I suspect some of the heel stick programs never had to address.

>> Good point.

>> We have had some questions from the Internet audience come in. One is what are the potential penalties for disclosure violations under HIPAA and FERPA?

>> I don't have those provisions right in front of me but there are potentially fines under HIPAA. If there is an investigation that -- if a complaint is filed, investigation is conducted and it's determined there was an unpermitted disclosure, HHS administers HIPAA, the Office of civil rights has regional offices that receive complaints and conduct those investigations. Under FERPA, the -- there isn't a specific sort of fee that can be charged to that individual entity. Rather, it relates under Part C to the lead agency's compliance overall under Part C and any complaints that are filed for example they can be filed through the state complaint process, the lead agency would have to respond and ensure corrective action. If a complaint was filed with a federal office there is a complaint right and investigation right and federal funds could be impacted. So slightly different structures in terms of the penalty scheme but similar requirements to have a complaint and hearing right under both. Although they're administered by completely different types of entities and there are two venues under Part C. FERPA applies on its own right and not through Part C then there are hearing rights under FERPA as well. Other questions?

>> Another question from the Internet audience. In Colorado we have a contract with the university hospital program to provide service coordination and IFSP to newborns in the metro area. We have had difficulty determining in the information for these Part C eligible children. In the -- have rights only FERPA and HIPAA? Does FERPA apply in these situations?

>> If it's unclear to me whether -- it sounds like the hospital is maybe receiving -- could be receiving federal Part C funds if it is providing service coordination -- and for those children who have ISSPs or been referred into Part C, the Part C confidentiality provisions would apply and that includes the protections of FERPA. If the hospital is a covered entity and the children haven't yet been referred -- and the hospital is a covered entity. It would appear that the confidentiality provisions under HIPAA would apply and the only question is if that same child is being served at the hospital through other hospital programs as well as being provided coordination services under Part C then arguably during that wonderful twilight zone where both could apply and that is certainly an option.

>> Another question from the Internet audience. This one comes from Wendy Thomas. Since each state has specific needs and statutes, is there legal assistance available for us to access on an individual basis?

>> I'm not sure what you mean in terms of the state laws? I would refer you to either your attorney general's office or your agency's general counsel. In terms of individual requests for clarification with respect to the federal laws, if they relate to Part C of IDEA that's administered by the Office of Special Education Programs, they relate to HIPAA that is administered by the Office of civil rights and HHS, their websites are included in the handout material and, of course, if FERPA applies directly on its own not because it's Part C you can also contact the compliance office within the U.S. Department of education.

>> That's all the questions from the Internet audience. Are there any on the telephone line?

>> This the Karl White from Utah. In response to one of our earlier questions you outlined the circumstances that would generally apply where Part C could not disclose individual information back to EHDI about whether services were provided to an individual child and whether that child was enrolled or not. Could the Part C program provide aggregate information back to the EHDI program if they said how many children were enrolled, how many have ISSPs, at what age did they enroll? What is the average age of enrollment? Things that would be useful for quality control and program evaluation.

>> There may be circumstances under which that could be provided. The two cautions I would have is make sure it's not personally identifiable information that would include information that could reveal the identity. If that's aggregated data is on two kids or five kids or aggregated by region as to identify that child, that would be a concern because it would be disclosure of personally identifiable information. The second is even if it was, there might be an arguable exception if the EHDI program had some sort of contact and research that Part C was interested in. If it doesn't have personally identifiable information in it, that data -- then the confidentiality provisions really wouldn't apply because you're not disclosing PII under Part C. That's a good suggestion. It talks about overall program identification rights.

>> Any other questions from people on the call? Okay. Then I think we'll bring this to a close. We appreciate your time, Kala, and as I hope all the people on the call know, the transcripts from this, as well as an audio feed, the power points and the handouts will be available on the mchcom.com within a few days. By sometime next week, I'm sure. So that you can go back to this and we thank you, Kala, for giving us some very useful information and we look forward to pursuing these issues in the future.

>> You're welcome. Karl. I hope this information is helpful. If you have additional questions my contact information is on the handouts and you're welcome to also contact me through Karl if you have more bigger programmatic questions.

>> Okay. Thank you, everybody.

>> Take care.