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>> EVELYN KEATING: Thank you to those of you who have joined us. We will get started in about five minutes.

Thank you for those of you who have joined us. We will get started in a few minutes. If you are calling in and on your computer, please be sure that your computer speakers are muted. Thank you.

(Noises in background)

>> EVELYN KEATING: Welcome, everyone. Thank you for joining us. We've reached our start time. All participants have been muted. If you have any comments or questions, please use the chat box today. This meeting is being recorded, and the recording will go out after the meeting.

Check out the attachment pod for the slides from today's meeting. This presentation was made possible by the preschool development grant birth through five initiative from the office of child care, the administration for children and families, US Department of Health and human services.

We're excited to have our experts on today to talk about data privacy and without further ado, I'll pass this over to Jim Lesko to get us started.

>> JIM LESKO: Thank you, Evelyn. So happy to have this opportunity to introduce our next in a series of webinars being supported by PDG B- 5 on data integration. Today's webinar will be focused on data privacy. And our presenters will be Ross Lemke, Sean Cottrell, both with AEM corporation. We'll be fortunate to have Whitney Phillips and Stephen Matherly both from Utah who will give us state level experience and opportunity to hear how they process through the data privacy elements within their state.

Today's community of conversation is an invited opportunity for our PDG grantees plus their partners and their consultants as part of this conversation. The PDG B- 5TA team are also on the line today as are, most likely, some federal project officers, some of the regional office specialists, and finally our partners with the state capacity building center.

We always like to make sure that we say that these conversations are voluntary in nature and we're glad that you're here.

This is an open discussion. The presenters have asked to please use the chat box to pose your questions. So you'll see that on your screen, and there will be lots of opportunities to respond to your questions, both directly from the presenters and hopefully from some of the state representatives that will be on the call.

So our privacy conversation we'll look at overview of privacy laws relevant to the regional development grant, state experiences with privacy challenges in the use of early childhood data, participant questions, and we'll have some closing slides and comments.

So I'm going to turn this over to Ross and Steve -- Sean,

sorry. I'm not sure who's going to take it on next.

>> SEAN COTTRELL: This is Sean. I'll give us a quick introduction. Myself and Ross Lemke who is the director of the privacy technical assistance center where we focus on supporting districts and states with the federal -- FERPA which will be the topic of discussion today. My name is Sean Cottrell I'm expert with PTAC. I joined the team in January 2018 where I was the privacy officer for the state of Wisconsin. More importantly I served in the capacity as interagency data governance coordinator for Wisconsin's early childhood integrated data system working with the department of children and families and the detection in combining their data to create an integrated data system. Today's webinar we encourage you to ask questions throughout the presentation. We will be devoting time towards the end of today's webinar to answer as many questions as we can.

And even if you don't have any questions, maybe there's something you're struggling with and you're looking for some feedback or anything like. Please don't hold back. We'd be more than happy to work with you outside of this webinar if you do have any more lengthy type questions. Don't hesitate.

Without further ado, we'll dive in.

Looking at privacy in a nutshell, over 100 countries have privacy or data protection authorities. Those models fall into three distinct sort of shapes. First is a very comprehensive approach, very prescriptive saying what you can and can't do, and telling you how to do it. There's also a self-regulatory approach where it's very hands off where industries regulate themselves. They create the standards and the metrics to manage those models of privacy.

Then we have the sectoral approach which is what's applied in the United States. You can think of the sectoral approach to privacy when you think about health privacy with HIPAA or education privacy with FERPA. We also have additional federal privacy laws that we'll be talking about today.

Some of those additional privacy laws, other than FERPA, or the individuals with disabilities education act, part B and part C which apply to children with special needs or disabilities in the early childhood sector. We'll briefly touch on HIPAA, the health insurance portability and accountability act. We'll talk about the Head Start program performance standards and state and local laws.

Without further ado, I would like to introduce Whitney Phillips who is the current privacy officer for the Utah state Board of Education. And Steve Matherly to share their struggles and pain points they've experienced and an opportunity to talk about some of the successes.

Whitney and Steve, I'll turn it over to you guys.

>> WHITNEY PHILLIPS: Thanks so much. Yes, like was mentioned my name is Whitney Phillips, the chief privacy officer

for the Utah state Board of Education. Many of you might be working with SEAs, state education agencies, some of you might not be. Just to give you a little background, many of -- many states, SEAs, do not actually have a dedicated person for student data privacy. Utah's unique in that regard.

So you won't always have someone at your disposal, but what I think Steve and I want to provide for you are lessons learned so that you don't have to -- you don't have to struggle as much as others.

You know, Utah has a unique early childhood data system, just like every other state. Things are set up differently. So some of the things that we might talk about aren't going to directly apply. But, for example, our Utah Department of Health includes home visiting, title V, part C Medicaid program where the Utah state Board of Education which is the state education agency. We have funding from SLDS branch, Part B, Title 1. Then we have another organization division of workforce services that actually has taken over our SLDS database. They work with Medicaid eligibility, child care subsidy, TANF. And Steve knows much more about these things.

I think one of the biggest takeaways is that it's extremely important for the cross-agency leadership, the data stewards, and the stakeholders to have an understanding of the legal requirements for their program, the privacy requirements for their program and also security and working with those tech vendors is important as well. I think -- I don't know if Steve is on -- is able to speak yet. But what he can speak to I think is more granular level is there are a few existing documents that we relied on heavily that will help solve a lot of your problems. So, Steve, what more do you have to say?

(Silence)

>> JIM LESKO: Steve, you probably need to hit star 6 because we can't hear you.

>> WHITNEY PHILLIPS: We'll give Steve a minute. I know he's on the call and listening. We're chatting, so he's going to be able to speak to this. While Steve can interrupt me when he gets back on, but I think some of the lessons learned that Steve kind of has spoken to me about was to look at the political landscape and the political will, because this will certainly affect your success and sustainability that will -- they will be asking questions of will one agency facilitate and lead the early childhood integrated data process? Who will make those decisions? What kind of data governance structure do you have there? Where will the data be centralized? Who will have access to it?

I know with our system there were a lot of growing pains because of staff turnover in different agencies. It seems like -- I think Steve can speak to that.

>> STEPHEN MATHERLY: Hello, hello.

>> WHITNEY PHILLIPS: Hi. We can hear you.

>> STEPHEN MATHERLY: Oh, wow. Sorry, everybody. I thought I'd be able to connect just through my computer audio, but I had to call in. Thanks for your patience. Yes, Whitney's got it right.

We all our early childhood integrated data system called E-KIDS. You'll hear me refer to it as ECID. Each one is unique throughout the station. Our ECID is at the Utah Department of Health. We've been working on it for seven or eight years now. It doesn't happen very fast. We weren't raised to the top in the early challenge state. But we made sure but steady progress using blended funds from our early childhood comprehensive systems grant and through funds from our partners to facilitate the child care development block grant over at DWS.

Additionally, another thing that took us awhile we had to build our matcher system. We wanted to build a matcher system that would benefit the entire department and not just for our E-KID. Those are important considerations. Right away a lesson learned is if you were considering establishing an E-KID, will you be able to tie into your state SLDS matcher database or perhaps another agency has one, or will you be developing your own? And then -- yeah, Whitney touched on -- we're very unique in Utah. I think if we can pull it off, many states should be able to. We're loading data right now. Reports are coming live right now. Our ECIDS at the department of the health, our SLDS grant is at the Utah state Board of Education which passes over to our workforce services agency to fund and administer the database.

Programs that we have at the Department of Health are home visiting and WIC and Part C and Medicaid and child care licensing. But we're reaching out to additional partners.

You can think of it this way, our role is to bring in the non-Utah state Board of Education pre-K data. So whatever doesn't fall under their umbrella, that's our job to bring it in. We're working with our Head Start partners and our child care assistance partners as well as Help Me Grow and others. The Utah state Board of Education they have the state pre-K data, but we're not universal pre-K yet in Utah but we have many grants for high quality pre-K services. Obviously we have Part B and Title I. So we rely -- we will send our data 2017 the state passed legislation which created this Utah Data Research Center. They do that with state and SLDS funds.

We will send our data to the Utah Data Research Center. That's already in place. I'm speaking specifically to our E-KIDS and the Utah state Board of Education and they will send their data as well as kindergarten assessment, DIBLES, language literacy, things of that nature to the Utah Data Research Center. Together we will be able to establish a distinct number of kids served, the frequency, the dosage, we can really build from just having some kind of basic quantitative type of analytics. And we can really get into impact and outcome

research.

So -- I mean, as been mentioned already, it's extremely -- lessons learned -- extremely important to have supportive, cross-agency leadership at the very top. You must have EDO support. Your data stewards have to be involved, your technology department, whether that's internal or external. All stakeholders that you intend to contribute data to your system need to be involved in the beginning and throughout, especially as you co-create your data sharing agreement and our data governance manual. That was a lesson well learned for us. We were dragging for awhile. We were having a hard time getting our Head Start on board. That's because they have they had a very valid point. The voting structure we had set up wasn't very equitable to the individually operated grantees. We worked hand in hand and developed a very comprehensive data governance manual that everybody felt that it was equitable as well as streamlined data sharing agreement. Once we had those things in place, it really lent to swift progress.

Other things kind of a laundry list of lessons learned. Like I mentioned, EDO support. What about political will, political leadership? We've had this legislation that created the Utah Data Research Center. We also have legislation that speaks to an early childhood governors commission or cabinet. These have lend to making progress with regard to data integration.

You'll need to decide, are you going to have a lead agency host this database or multiple agencies or is it going to be a not for profit, someone that can kind of facilitate -- it might not have necessarily a lot of data or any data in the game, but they could serve as a hub, or is it going to be one of your state agencies that takes the lead.

And then a lot of states they've -- what they've constructed is an early childhood board, an office of early childhood where you have underneath one roof, you've got your Part B, Part C, pre-K, Head Start, child care, Title I and so forth. If it's under one roof, that will help move things forward. Let's set an example it doesn't have to be that way if you keep the lines of communication open as well as working with PTAC and others to establish effective and legal data sharing agreement.

Other considerations is what kind of system are you going to set up? Whether that be centralized, federated or a hybrid. I will stop there because I know that's the presentation for next week.

Another thing importantly to consider, will this be a research database only, or will it have operational capacity such as triages, referrals, case management aspect. Or will your ECIDS be purely for research purposes. Then as I mentioned earlier, are you going to be able to tie into an extraction transfer and load your matcher database, or will you start from

scratch and build your own? Keep in mind you're going to need money for ongoing maintenance and enhancements for additional data elements and such and for your ongoing sustainability. I'm talking kind of a quick because I know I took a minute to get on the phone.

Lastly, and we'll let the questions fly, as I mentioned co-create your data sharing agreements with your partners as well as your governance manual. Develop and distribute both at the same time. Here's the trick. You've got to create document, whether foundational, processes that are foundational and firm enough to facilitate your objectives, yet they need to be flexible enough when there are changes in political will or leadership or legislation, things of that nature. It's very, very important to document all your decisions and agreements along the way. Believe me, you're going to see turnover, and you don't want to work very hard through certain processes, come up with agreements and understandings, and then have a little bit of turnover, and then have to do all that over again. Speaking from everything I've been saying have been lessons hard learned. Get with your technology people up front. Make sure that you're setting it up with your segmented server network and isolated databases and things of that nature so that you're FERPA compliant.

Lastly, and we'll take any questions. I wish -- two things. I wish I had the slide deck that the presenters at AEM have put together today. It's very wonderful to see all the FERPA stuff and other things such as HIPAA in one place. A few years ago when I came on board to work on this, I had to look everywhere for all these different documents, try to piece them together and learn from them. The slide deck from this webinar is invaluable. It has the citations and sources which is wonderful. I would encourage anybody who's working on SLDS or ECIDS, if they want some wonderful knowledge as well as a few good laughs to read an unofficial guide to the why and how of state early childhood data systems. An ounce of prevention fund by Elliott Regenstein, if I said his name right, I hope. That was so good for me to read when I was in the middle of this. It was written in a way that's very informative and a little bit of tongue in cheek and entertaining. It's good stuff.

Whitney and I threw all that out. Let's make sure we're good on time and questions and things of that nature.

>> SEAN COTTRELL: Steve and Whitney thank you very much for providing that insight in the experience in Utah. We're going to hold questions to the end of webinar. Diving right into FERPA, if we look at FERPA from an 80,000 view we can sum it up in these key bullet points. FERPA gives parents and eligible students the right to access and seek to amend their children's education records. It protects the personally identifiable information from education records from unauthorized disclosure and additionally it imposes requirements

for written consent before sharing personally identifiable information unless an exception applies.

So what is this concept of P which is what FERPA protects? PII embodies direct identifiers such as a student's name, Social Security number, maybe a student ID number, it's that one-on-one direct relationship to the. But it embodies other identifiers such as student's birth date. When we're looking at aggregate reporting for groups of small populations or populations with sensitive characteristics we might be able to identify the single white female in a class of five which is why we talk about disclosure avoidance. What are education records.

>> Please enter your pass code followed by the hash --

>> SEAN COTTRELL: Education records under FERPA are records directly related to the student and maintained by or on behalf of an educational agency. The definition is very broad. What rights do parents and eligible children have. They have a right to inspect and review education records. They have the right to request --

>> When you hear the tone --

>> Education records, the right to consent to disclosures with certain exceptions and a right to file a complaint regarding an alleged violation of FERPA.

If you are using consent as the general rule, we recommend it be baked into the registration process. Consent under FERPA is fairly prescriptive. FERPA says consent must specify the records that may be disclosed, the purpose for the disclosure, and identify the party or class of parties to whom that disclosure will be made. Additional consent should be signed and dated but does not have to be in pen ink. It can be done electronically as long as the identity of the parent, in your cases especially in early childhood, as long as that parent's identity is appropriately authenticated. If you do have parental consent to disclose early education records, generally there's an exception that you can continue the work that you are doing. School officials have access to education records when appropriately compliance pieces are met. Schools where students seek to enroll. There are additional study exception and an audit and evaluation exception. We're going to dive into some of those in the next few slides.

Legitimate research under FERPA. It doesn't really speak to research. It talks about studies, and it talks about audit and evaluation. Research and evaluation under FERPA can happen legitimately either with content of one parent or the eligible student. An eligible student would be for any of you guys running programs that have that "Doogie Houser" in them. There might be some young children enrolled in college. FERPA says once you turn 18 or enroll in college, the FERPA rights transfer from the parents to the students. I would recommend if you're in one of those situations, that you reach out to PTAC for

additional guidance.

The studies exception under FERPA is fairly straightforward. The studies exception requires that if you do not have parental consent you can only provide data to develop, validate, or administer predictive test, administer a student aid program or -- most fall under the improve instruction. If you're using the studies exception to disclose PII it's very important that you articulate how that particular activity is for the goal for improving instruction.

Under the audit and evaluation exception, again very similar. However, that activity must be to audit or evaluate a federal or state supported education program or to enforce or comply with federal legal requirements that relate to those education programs. An audit evaluation or enforcement or compliance activity.

As far as early childhood education programs, under US education code 1003, the term early childhood education -- this is where you're going to focus on that last bullet there is state licensed or regulated child care programs. Again, Head Start programs fall under this early childhood program. For PDG B-5 program that's funded by the US Department of Health and human services. Generally when we look at the applicability of FERPA, we say follow the funding stream. If your program is funded by the US Department of Education, then FERPA applies. In your guy's case, early childhood development programs are generally considered under this definition to meet the definition of an early childhood program thusly FERPA would apply to the records maintained by your program.

Again, that program serves children from birth to age 6 that address the children's cognitive, social, emotional, and physical development.

Now, I'm going to go ahead and turn it over to Ross Lemke, the current director of PTAC.

>> ROSS LEMKE: FERPA represents that 500-pound gorilla in the room as privacy goes. It's the granddaddy of education privacy laws. After FERPA was enacted in 1974 with an IDEA Part B and Part C. Individuals with disabilities education act. Part B is for school aged children as well as ages 3 to 5 part B619. Part 6 is for your early childhood special education children.

So there are confidentiality provisions in both statutes. Now, both of them look very, very similar to FERPA in many respects, but there are a few key differences. So if you are starting to link to early childhood data in Part B or Part C, it's important to look at both statutes just to see if there's any additional protection that you need to enact as a result of using that data.

So to whom do these three statutes apply? FERPA applies to educational agencies or institutions. Any public or private agency or institution that provides educational services or

instruction to students or is authorized to direct and control public elementary or secondary or post-secondary education or post secondary educational institutions. I think the most important bullet, to which funds have been made available under any program administered by the Secretary. In this case we're referring to the Secretary of Education. FERPA is a follow the money statute. If you're receiving services from a program administered by the Department of Education quite likely you're subject to FERPA.

IDEA part B applies to a participating agency that collects, maintains, uses personally identifiable information or from which information is obtained under Part B.

And Part C has a very similar definition. The definition under Part B but of course references Part C.

An important note to understand on IDEA Part B and Part C is the office of special education programs at the US Department of Education has a different perspective on the appropriateness of certain exceptions under FERPA. Generally the use of the studies exception is not seen as an appropriate exception for the use of IDEA Part B Section 619 or IDEA Part C data. Generally it subscribes to that you should be using the audit or evaluation exception.

So if you have some sort of project that wants to use the studies exception for these types of data elements, I highly recommend that you reach out to the office of special education programs to work with them to see if exceptions would be appropriate or how to make that particular request to work under that particular audit request evaluation.

So outside of education law, we have some other statutes. Health insurance portability and accountability act of 1996, otherwise known as HIPAA. Everyone in this audience should be somewhat familiar with it. Everybody has probably gone to the doctor's office at least once. This law was enacted to establish certain protections around health data, insurance data. It required standards for the exchange of electronic information, things like billing code or payment for health services.

It set a process and a timeline for establishing privacy and security protections for personal health information used in those electronic transactions.

There are a few definitions, who has to comply. Whereas in FERPA you might have educational agencies. In HIPAA you have covered entities. It could be a health plan or your health insurance. Healthcare providers, that could be your doctor or nurse. Healthcare clearinghouses, these are entities that have standard information into standard format. Applicability of HIPPA privacy protection is not dependent of the recipients of federal funding.

Business associates need to comply. Individuals or organizations performing a service on behalf of the covered

entities. Or provides services to a covered entity. And services that involve the use and or disclosure of protected health information.

Some examples of this could be an entity that helps the agency whose claims processing and billing third-party reimbursement such as Medicaid or private insurance. A private legal firm that has access to private health information in the course of its work or a technology company that has access to protected health information while working on fixes to a State data system.

Under the HIPAA privacy rules there are certain individual rights. There's a right to receive notice of privacy practices. You normally see this when you go to the doctor's office. Who can access those records? There's a process in place for correcting and amending those records. There's accounting for disclosure. So there's recordation requirements under HIPAA, much as there are recordation requirements under FERPA. There are restrictions on information sharing. There's a means of confidential communication.

HIPAA is more prescriptive in terms of data security and how institutions can converse with each other under technology standards. FERPA relies on something called reasonable methods which is much less prescriptive and much like FERPA, you have the right to file a complaint if your rights under HIPAA have been violated.

So on September -- before I go into the HHS new rules on Head Start I would state that a lot of times there are some intersections between HIPAA and FERPA. With my children if I want them to go to school, I have to get them vaccinated. I go to the doctor's office and I go and they get their shots. The information that the doctor's office is maintaining on my children is protected by HIPAA. When I get a copy of those vaccination records and I walk them over to walk them over to the school and then -- once the school takes them and maintains them they become protected by something called FERPA. Basically joint guidance years ago between HHS and Department of Education said if it is a medical record that is maintained by the US department of -- maintained by an educational agency, then FERPA protections are in place as opposed to HIPAA protections. There's a good resource document on PTAC's website that answers a number of questions about the intersections of HIPAA and FERPA. I would certainly encourage you to take a look at those.

Moving on. So back in 2016, the office of Head Start announced the Federal Register a comprehensive revision of the Head Start program performance standards. This is the first one since their original release in 1975. So as part of these new performance standards, there was a section, sub part C that went to the privacy of child records. Subpart outlines certain requirements to protect personally identifiable information in child records. So you'll notice in the following bullets here

some of these key components. Parental consent including nine instances when consent is not required.

So written agreements with third parties to protect PII when disclosing data. Parent rights in respect to their child records. A right to inspect, amend, request a hearing, and a copy of record, and also a right to inspect written agreements.

There's elements there on maintenance of records. The data destruction or reasonable time frame. Ensuring that only appropriate parties have access. Then data systems are protected to current industry standards. There's an annual notice to parents.

For those of you that work in the K- 12 or early child education where FERPA is implicated you'll notice there are a whole lot of similarities between these new privacy protections under Head Start as well as FERPA. It they're very similar in many, many respects.

So in that some subpart C it states that if a program is subject to FERPA, for example, a school district, then the program does not comply with the subpart. If it is a school district early childhood program then FERPA. If they're under the confidentiality requirements that I talked about earlier, then the program follows those requirements of the child record and not this subpart.

So there's an exemption to consent in the early childhood integrated data system, to disclose PII without consent to officials from a federal or state entity to evaluate education or child development programs, provided that some control is in place such as a written agreement. This standard allows a program to share PII with their state data system without parental consent for the purpose of evaluating education and child development programs.

This is analogous to the audit and evaluation exception under FERPA. That hyperlink below links you to the language in the regs.

Finally something that everybody should keep in mind is that FERPA and the rules under Head Start and IDEA, these really represent the floor for protection of student privacy not the ceiling. There are many states and local laws on the books that might add additional restrictions on how you collect, maintain, protect, and use data. As you are beginning to go and build or continue to build these integrated data systems using early childhood data, you need to be cognizant and aware of the laws that are in place in your own state, perhaps even county or if you have data from Indian tribes, tribal law might apply.

As part of any project, whether it's with an integrated data system or specific research project, you should begin those projects by reviewing all of the relevant privacy laws both at the federal level but at the state and local level. In many cases as you've seen before, many -- more than one law might apply to the data.

So the next couple slides list some resources we have available for you. The first links here are from the privacy technical assistance center that is operated out of the United States Department of Education student privacy and policy office. These are technical assistance resources. There are many that focus on early childhood. The integrated data systems and student privacy talk about joining multiple systems together and the FERPA exceptions that apply to joining.

There is a document on understanding the confidentiality requirements applicable to IDEA early childhood programs. This was produced by the -- by OSEP. Talking about student directory information, best practices around the authentication of somebody's identity when trying to get access to data. There's a crosswalk between the FERPA statute and the IDEA statute.

Some advice on data deidentification discussing basic terms as well as frequently asked questions around disclosure avoidance. There is an early childhood integrated data systems tool kit.

Then also there's some resources outside the Department of Education. The Department of Education does fund some technical assistance centers around the use and protection and collection of IDEA data. Both the IDEA data center, which is the first link and the DaSy center have done work over the years in the confidentiality in the IDEA sense. And then the last two links link to some Head Start resources, the first of which is the new Head Start performance standards 1303 subpart C to focus on the protections for the privacy of child records. And then there is a Head Start FAQ for the last resource there.

So I am going to pause for a moment, and we have some time here for questions or stories from the field, if people have horror stories or lessons learned, or questions about any of these statutes, we would be interested in hearing from you.

>> JIM LESKO: So Sean and Ross, we did have one question in the box, and it was regarding ownership of each student's data. Are integrated data owned by advisory council, a cabinet agency or a data governance committee or other governance bodies? Do you have any --

>> SEAN COTTRELL: This is Sean. Absolutely, thank you, Jim. That's a very critical question that should really be addressed prior to developing out your integrated data system. Generally what we would look towards is for a data governance program to determine whether or not the data is efficiently deidentified and owned by a central early childhood group or cabinet agency. However, a lot of the ways -- what we generally see across the field is education data maintained in an early childhood data system is usually owned by the education body, just like health data would be owned by the health body and data from children and families or other programs would be owned by those individual programs.

The reason we look at this is that when that data is

going to be used, we look to those groups to really inform the use of that data to make sure that if we're using health data while the health organization should be the experts on the use of health data in compliance with relevant federal and state health laws. So we would want to look to those experts and kind of leverage some of those expertise from our partner organizations in order to really develop a robust data system.

I hope that does clarify it. Additionally, ECIDS tool kit does a good job of addressing data governance. I know this is the third webinar in a series. I believe the first webinar was all around data governance, and it with as put on by a few folks from our team. Again, ownership of data is really critical because you want to make sure you're using the data in an effective, informed, and a compliant manner.

>> JIM LESKO: Sean, this is Jim. This raises another question that I have related to your answer and Mary's question. When a state or local entity enters in to a process where they are sharing data, most likely, I guess, deidentified -- I'm just going to use the term sharing data. Does each entity make the assumption that they have already complied it with their own privacy rules? So the question is, because in early education we may be sharing data both from education and from health and maybe family services. So as those agencies make their data available to that single source who's aggregating the data, is the assumption then that each of those agencies complies with their own privacy regulations? Have you had that?

>> SEAN COTTRELL: Yeah. That's an excellent question. Generally when we think about deidentified data, we think about data that's reported in the aggregate or at the program level or the state level where we're not really talking about individual student level records. In that case, again, the recommendation would be, depending on, again, local state laws, things like that, if there's prescribed disclosure avoidance requirements or other methodologies that need to be applied we look to those organizations to inform that process.

For example, if we had three-state organizations who were contributing data to a hybrid federated data system, what we would do is we would look to those organizations and say, who has the strictest requirements for privacy? Sometimes, again, different state organizations might have small end sizes, they require that we redact numbers when they're reported a certain threshold and that additional privacy safeguards be put in place. So we would, again, recommend that that conversation happen prior to either developing the system or definitely prior to reporting out that data.

It is generally straightforward once you identify those business rules to, again, identify what's the most strict and apply those business rules when you are reporting that data.

Jim also mentioned deidentified data. Again, deidentified data is generally when all personally identifiable

information has been stripped from -- let's use a data report, for example. It would not be sufficient -- it would not be a sufficient level of deidentification under the guise of FERPA just to remove the student name and the student ID number and then report all that data in the aggregate. FERPA would require that extreme populations, for example, if there is only one child who falls into a specific category or if all children fell into a specific category or showed a specific outcome, it would be disclosive to a reasonable member of the school community which children received which outcomes. So that's really why when we look at integrated data systems including with ECIDS, generally FERPA is going to be the strictest. I do say that with keeping in mind that HIPAA does have additional privacy considerations and for everyone on the phone, if you ever reach out to PTAC this question will generally be met with the response of "it depends." And it depends really has to do with us having a conversation to find out how is that data being used, where is it coming from, how is it being reported, where is it being reported, and things like that.

I do see another question that just came in. I'll go ahead and read that out loud for everyone. We have someone who is interested in knowing how to handle data release in the case of parents who are not together when the family data is involved.

So generally under FERPA, FERPA does not have consideration for custodial parents. So just because the mom might have custody of the children does not mean the dad is not afforded rights under FERPA. We would look to either a court order that would strip one of the parents of their rights, and then that court order must -- should be included in your program or at least in the considerations before providing access to a parent.

Again, looking at today's sort of environment and landscape, sometimes there might be protective court orders in place where due to threat of harm or violence, one family member might -- there might be a court order that restricts letting another family member know the whereabouts the physical location of those other family members. This is kind of a tricky conversation. Definitely it depends would be applicable here. But I would recommend whoever asked this question to check out the PTAC website. We have a lot of guidance there for working with parents and what those policies and practices in an education type environment should address and what other considerations should be applied when you're getting a request.

Ross mentioned that identity authentication best practices guidance. I believe that touches on this very concept. So, again, I would encourage you to peruse some of those resources we provided in today's webinar. And if you can't find those resources on our website, again, please go ahead and shoot us an email through the contact us button at

studentprivacy.Ed.gov. We'll have all that information at the end of today's webinar.

>> ROSS LEMKE: I wanted to add a couple extra points on what you addressed. As far as the deidentified data goes, Sean talked about data in more of an aggregate sense. Something we do here in the field a lot is sort of concept of deidentification. It's just something to be aware of as -- if you're sharing child level data, depending on where it's getting sent and the appropriate agreements in place, the deidentification oftentimes isn't -- it's sometimes more involved because if you have populations with small or unique characteristics, you might be able to go back and reverse identify somebody.

Also, to go back to Kim's question about if the parents weren't together anymore. One sort of lesson learned from the field is that both FERPA and the Head Start regs have a 45-day access requirement. So while, yes, under FERPA both custodial parents and noncustodial parents have access. If there is something off about the request that the child in question has ohm been associated with that one parent, and now this other parent has come out of nowhere and although they're requesting access to, is not how the child was doing in their own program but the emergency contact list for that child. That might raise enough red flags that you might want to take advantage of that 45-day window to get to the bottom of what is going on with this specific family.

I'm going to pause for a second and hand the mic over to Steve who wanted to share one more important lesson learned in the last five minutes that we have here.

>> STEPHEN MATHERLY: Yes. Thank you. Can you hear me okay?

>> ROSS LEMKE: Perfect.

>> STEPHEN MATHERLY: Can you hear me?

>> EVELYN KEATING: Yes.

>> STEPHEN MATHERLY: Oh, good. As I was listening to Sean and Ross, I thought of one of the important lessons I've learned since I've been working on this three or four years. When I came here, we thought we were going to adhere to FERPA, that's one of the highest rules, regs, with regards to protecting data and privacy. So we were -- we designed our systems and data sharing agreement and our data governance manual with very FERPA centralized. However, there's a drawback to that or something to keep in mind. Here's the lesson well learned. You cannot utilize the FERPA audit and program evaluation exception for data for programs that aren't covered by FERPA. We were going to use the FERPA audit evaluation exception, but you can't use that for WIC or home visiting or Help Me Grow programs that don't fall under the FERPA umbrella. What we've done in those situations, being uniquely situated at the Department of Health is making sure we're getting the proper parental consent with a

program like WIC we worked with their feds and worked with their code and with the local program leaders to make sure we were lined up and we had parental consent in place. Very similar thing we did for home visiting. With regards to HIPAA, sent our matcher database at this point in time is not HIPAA certified, HIPAA approved. If it's HIPAA data or if a parent might be in a situation where they think it's HIPAA data such as doing an ASQ in a doctor's office, then we have the parent release those HIPAA protections. So that's how we were able to do our ECIDS here at the Department of Health is when we could utilize FERPA and the exception and in Head Start which is very similar. That's what we did. You have to look at each individual data source and see what governs that data. The mistake we had in place that we would be able to use that audit as an evaluation exception for all of our early childhood programs. And that's just not applicable.

>> SEAN COTTRELL: Steve, that's a great point. One additional piece I would like to add. Again, with parental consent, you don't have to worry about any of those exceptions because you have the consent. Again, having parental consent includes that step during the registration process for your program. Have the parent sign off and be transparent. Let the parents know that you do evaluate the effectiveness of this program, and that's what that student data will be used for. The only identifiable data being used to match student data across different agencies and things like that. Again, having those considerations during the development phase of your data systems is very -- those conversations are control critical to have at early steps as to how you can perform those matches

>> JIM LESKO: Okay. Great. I don't see any other questions in the chat box. Thank you, Ross. Thank you, Sean. Thank you, Steve, very much for the webinar today. Great information. A lot of information. We would love to hear back some feedback and suggestions if you have any. There's a survey. You can directly link to that survey from this slide if you would like to give us some feedback today. We will also be sharing the recording of the webinar along with the slide deck following this event. And we'll have a link to the survey monkey there as well.

Without any further ado, I see we're at 4:00. Thank you, all, for joining this communities of conversation today. Thank you again to Ross and Sean for bringing this information, putting it together into a slide deck and sharing it. Thank you to the Utah team as well. I want to give a shoutout to the PDG B- 5 team who behind the scenes have been hosting and managing this and a special shoutout to (?) today. Thank you very much and have a great rest of the week.

(Webinar concluded at 3:00 PM CT).

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