

Colorado Children and Youth Information Sharing Collaborative  
Meeting Minutes  
December 21, 2011 9:00 AM – 11:00 AM  
Location JCJAC – Large Training Room

**CCYIS Vision:**

*Children, youth and families experience seamless and collaborative services and supports that are responsive to their interests and needs. This is facilitated by information sharing that safeguards their privacy at both the state and local level.*

**CCYIS Mission:**

*To develop strategies for sharing information to optimize services available and delivered to children, youth and families in Colorado.*

**Attendees**

José Esquibel, Director IPS, CDPHE  
Jeff McDonald, Director, Jeffco JAC  
Meg Williams, Manager, CDPS, DCJ  
Norm Kirsch, Manager, CDHS  
Dianna Anderson, OIT Director  
Jan Petro, Director CDE  
Anna Lopez, Grant Manager, DCJ  
Alisa Marlatt, Investigative Response Specialist, CDHS -CW  
Margie Grimsley, TA Coordinator, FFCMHCC  
Kelly Abbott, SB94 0 18<sup>th</sup> JD  
Julie Marshall, Professor, UCD-CSPH  
Sara Boylan, Director, Denver 1451  
Susan Colling, Judicial  
Sean McCaw, Data Supervisor, CDHS-CW  
Peggy Baikie, Program Mgr NP, Denver Health  
Troy Evatt, Data Manager, CDHS-DBH  
Allie Miller, Coordinator 1451 Morgan County  
Bill Fulton, The Civic Canopy  
Mae Washam Parent, SOC Member & Jeffco Parent Partner  
David Menefee, CDHS-DBH  
Kat Foo, CDHS – HIPPA  
Kevin Custer, CANDO  
Ida Drury, CDHS  
Stephanie Rondenell, CND  
Russell Burton, CND  
Joan Masztaler, CND  
Sarah Caron, CND  
Susan Laniewski, Privacy, Sal Consulting/CND – on telephone  
Angie Wickersham, Director HTOP, Mesa County – on telephone  
Terri Anderson, El Paso County – on telephone

Minutes from the November 16, 2011 and October 19, 2011 meetings were approved with a correction from Susan Colling.

### **Action Items**

- Sara Boylan to send use case.
- José Esquibel will send out information on what goes on MOU.
- MOU on agenda for Jan/Feb CCYIS meeting.
- José Esquibel will send use case template to the School Resource Officers group.
- Norm Kirsch will send consent templates to Kat Foo for review.
- Sarah Caron will send link to the CCYIS webpage so the group can review the Governance Structure document.
- Sarah Caron will find national Interstate Compact for the Placement of Children document.

### **Strategic Plan**

- Joan Masztaler covered the highlights of the Strategic Plan and that it been reviewed by the Leadership team and is out in the Box.net for review.
- Stephanie Rondenell expects to have edited copies for the January meeting.
- José Esquibel presented the goals of the Strategic Plan to the Executive Directors and felt that there was a solid green light to move forward with the plan.
- Susan Colling added that she has set up a meeting with Jerry Marroney and the new CIO Chad Cornelius, as well as a few other people from judicial to attempt to overcome some of the walls we've encountered with judicial.

### **Update Dianna Anderson – OIT**

An overview of the unique identifier RFP was presented. The purpose of the project is to provide the state's first data link. OIT will be using the SLDS (Statewide Longitudinal Data Systems) project which captures longitudinal data from early childhood through P20 graduation. This project has three pieces to it. These are: capture, link and provide stages. **Capture** is the data entry, where we get the data. **Link** is the piece is where we will link data from different systems. We are going to have a link from education to higher education to human services. **Provide** will be more of the business intelligence and reporting behind the system. The RFP is specific to the Link phase since we are trying to link data. We have multiple data sharing initiatives, the SLDS, the Early Childhood Development, Health Information Exchange and CCYIS. You can see the agencies which will be contributing to the link interface. There is some cross over between CCYIS and SLDS. We are going to do this through a master data management system which is a repository and a registry where we create a person ID. Each agency will have their own ID for an individual but link project will identify those ID's and will map them to each system and link them together. We will have data agreements and MOUs as a method to create an understanding what information is there and how we will exchange with each system so you can go out and get information from these different departments. All of this will be secure, especially with all the human services data. We've got all the policies and roll-back technology based security around all of this.

- Overall concept is the master data management that will create a person ID and with this ID a link will be provided between systems and agencies. As an example, if Dianna Anderson is in any system, the information will be pulled.
- Medicaid is not currently on the list of information to be provided however, HCPF will be included at a later time.
- Emphasis on starting slow and to get a proof on concept and then bring in other agencies.
- “Golden Record” has 14 data attributes.
- RFP vendor selection will be completed within the upcoming month.
- Stephanie Rondenell stated that she thought Sherri Hammonds had indicated that the second half of 2012, CCYIS agencies may be added. Dianne indicated that OIT wants to move slowly, however she would defer to the CTO on this item.
- 50% of the agencies that CCYIS wants to interact with will be in SLDS.
- State needs to begin using NIEM for its data exchange protocol.
- U.S. Department of Education is now looking at NIEM as their data sharing protocol.
- SLDS – Federal contact stated that they will have a NIEM exchange for other State SLDS programs and that this will move forward in June.
- David Menefee asked how long the SLDS grant was for. It is a 5 year grant from development through implementation. David asked what they could expect in CDHS at a client level. Dianna Anderson indicated that the initial scope is CDHS data going out to other agencies.
- Kat Foo added that as data is shared there is suppose to be a path that indicates which agency has the data, i.e. what does Human Services have that others need. No one knows what agencies have regarding data.
- Meg Williams explained the case studies/use cases will help to clarify what is the incident and when is the data shared. Also, that this fits well into the privacy work. What we are trying to find out is what information is out there and under what conditions are you requesting the information. That’s where the privacy group can come in and help set up some of those parameters. One of the first things you do is find out if that kid is even in the system, which is where the core record becomes useful.
- José Esquibel added that the Core Record would at least point to where the data is coming from.
- Sean McCaw commented that when the same data is captured by each agency it creates silos and adds to the cost.
- Dianna Anderson stated that’s what OIT is working towards. That’s also why we want to use a model like NIEM so they can be identified differently in the systems, but they’ll have a translator.
- Dianna Anderson indicated that the Colorado Information Marketplace will be where the information is and will point to the system that holds the data.
- Troy Evatt, CDHS has a lot of smaller data sets that don’t talk to TRAILS.
- Sean McCaw was making progress on this type of review with TRAILS. He has an excel spreadsheet that compares tables and what are common elements and where to find the date. Sean has been moved to another project which has slowed his progress on the TRAILS tables.
- Kat Foo added that part of the problem is with the different versions of Microsoft Office software that is being used. Many agencies are running with Office 2000 and so the

conversion of files is very difficult with agencies using Office 2007 or 2010. It is very difficult to get the data out of the old systems.

### **Key Audience/Stakeholder Review**

- Stephanie Rondenell reviewed the Governance Structure and asked the Collaborative if there were some additional groups not in the Governance Structure that should be added. Additions include:
  - Developmental Disability Council
  - Family Advocacy
  - Correct CCJJ
- The Collaborative can review the Governance Structure on the web-site to consider additional revisions.

### **Core Record Review**

- Stephanie Rondenell reviewed the Core Record that was developed at the last CCYIS Collaborative meeting. Document handed out had a comparison of CCYIS Core Record, MOJJIS system from Missouri, and the OIT Golden Record.
- Stephanie Rondenell reminded the group that the idea of the Core Record is that when you are working with a youth, enough information is presented that you can determine if the information presented is the data that you need.
- We also have what Human Services, Child Welfare and Judicial share from the DISH application and what the court and Child Welfare share from that same application.
- What we are trying to do is identify the data that you would like to see from the agencies that we are trying to share information. It has to be that snapshot because as it was said previously, this information may be correct today but tomorrow it may not be. A youth may be in Jeffco Public Schools today but tomorrow could be going somewhere else. We are just trying to put in all the data that we know you are currently collecting.
- CND added any information that was discussed from the collaborative meeting last month, and provided the MOJJIS information from Missouri.
- Meg Williams asked that now that there is an OIT Golden Record should CCYIS deviate from that record or adapt the Golden Record. Meg's question sparked discussion around alias, Sean McCaw said that often you don't see last name changes. Also general comments about ethnicity and race, the complexity and the importance of a consistent practice to have information entered correctly at initial set-up took place.
- Troy Evatt added that there are a lot of fields on the Golden Record that can change. Troy also discussed the SASID for education and the SIDMOD for Medicare.
- Meg Williams summarized the discussion that the CCYIS would recommend the following additions to the Golden Record:
  - Gender
  - Parent
  - Alias
- Mae Washam stated that her daughter in Littleton schools could use what ever last name she wanted regardless of what was on her birth certificate.
- Discussion continued around care giver information and the issues with adoption. Meg Williams reminded the group that our focus at this point is not to solve everything very

specifically but rather to have broad information that is basic and common across systems and agencies.

- Stephanie Rondenell brought the group to the Golden Record and Core Record. Once the search is completed and pulls back information, what is the information needed to know this is the correct youth.
- José Esquibel indicated that these ideas would be recorded in the meeting minutes and asked the group if there was acceptance of the Golden Record.
- Stephanie Rondenell summarized that some information needed by CCYIS agencies is missing on the Golden Record. The requirement for youth specific information drives the need for additional data.
- Meg Williams made a motion to request the following data to be added to the Golden Record:
  - Gender
  - Parent/Guardian
  - Alias
  - Caregiver
  - Removing SIDMOD & SASID as agency specific data.
- Norm Kirsch seconded the motion. Collaborative agreed.
- José Esquibel state that CCYIS will work with OIT to see if they can accept some of the CCYIS data as part of their golden record. José Esquibel added that the data requirements may change but we need to put a stake in the ground and move forward.
- Stephanie Rondenell, CND will update the list then add agency & what data they are looking for and then we will begin to fill in the rest of the data sheet.

### **Use Case Identification**

- Stephanie Rondenell reviewed the discussion from last month's meeting of the need for use cases as part of our work plan. To date CND has not received any use cases.
- Susan Laniewski reviewed a matrix that was completed, listing out a variety of events that require data exchanges. Most of the data exchanges come out of State & Federal statues. Instances where information could be shared is listed in the matrix along with:
  - What is the condition in which information would be shared
  - What agency do you represent
  - What forms and consent might be needed
- Jeff McDonald commented that the focus group they held developed 5 sceneries when youth come to the JAC. The JAC group pulled information together in 35 minutes. The items highlighted in pink on the matrix are the ones the JAC team completed.
- Susan Laniewski applied the state and federal regulation to the matrix. Susan suggested that the CCYIS identify potential use cases to work on to move through the data exchanges. There was some additional discussion regarding consent. José Esquibel indicated that there will be more in the Privacy meeting about consent.
- Stephanie Rondenell needs the group to select an instance to work on between and now and the next meeting.
- Meg Williams suggested something broad such as pre-sentencing. Sara Boylan has started a use case around this discussion. Sara will send to Stephanie when she has it completed.

- Stephanie Rondenell reminded everyone of the discussion about the initiation of an interstate compact data exchange. CND pulled down the Colorado handbook on how this was supposed to happen. We reproduced the flowcharts where Colorado is the receiving state and when Colorado is the sending state. We should consider this as a potential cross state data exchange. We could potentially look at this as a state to state data exchange. One of the things OIT is working on is a multiple state data exchange using Geospatial Information System (GIS) data and unemployment insurance claims across state lines. What are your thoughts?
- Meg Williams stated that there are two things to consider: Human Services has two ICPC specialists. One is Chantel Smith and DYC has Summer Foxworth. We need those people here before we talk about this as a potential data exchange.

### **FERPA and Proposed Hi-Tech HIPAA Updates**

- Stephanie Rondenell provided handouts with FERPA updates and proposed changes to HIPAA from a hi-tech perspective.

### **Agency Updates**

- Agenda item for January/February should include a review of the MOU with the existing state departments that includes CCYIS. We are being asked to renew that MOU and get a draft to the executive directors by March. It would be worthwhile for us to be thinking about how we want to revise the CCYIS parts of that MOU for the state departments to be reflective of where we want to take this initiative over the next couple of years.

### **Next Collaborative Meeting**

**January 18, 2012 – 9:00 AM – 11:00 AM**

**Location: JCJAC**



## December 2011 - REVISED FERPA REGULATIONS: AN OVERVIEW FOR SEAS AND LEAS

The U.S. Department of Education (the Department) has revised its regulations governing the Family Educational Rights and Privacy Act (FERPA). This overview is intended to highlight changes that may affect State educational agencies (SEAs) and local educational agencies (LEAs).

### Ensuring the Effectiveness of Publically Funded Education Programs

It is important that all students have access to a quality education. In order to achieve this goal, SEAs and LEAs must have the ability to disclose student data to evaluate the effectiveness of publicly-funded education programs – programs ranging from early childhood through adult education – to ensure that our limited public resources are invested wisely. The Department has amended the FERPA regulations to clarify the limited circumstances where SEAs and LEAs may disclose student information to assess the effectiveness of State and Federally-funded education programs – the audit and evaluation exception and the studies exception. (34 CFR §§ 99.31(a)(6) & 99.31(a)(3) and 99.35.)

We have highlighted examples in the list below of activities permitted under the new regulations. These examples are intended to be illustrative, not all-inclusive. We intend to issue a series of case studies to explain in more detail how SEAs and LEAs may comply with the new regulations. If you have other specific scenarios you think would be helpful for the Department to provide additional information on, please contact the Department's Privacy Technical Assistance Center (PTAC) at [PrivacyTA@ed.gov](mailto:PrivacyTA@ed.gov) or Toll-Free Phone: 855-249-3072.

- An SEA is authorized to conduct studies for or on behalf of the LEAs in their State. An SEA could, for example, study comparative program outcomes across districts to assess what programs provide the best instruction, and then duplicate those instruction techniques in other districts. Consistent with the previous regulations, an SEA would need to enter into a written agreement with the research organization conducting the study.
- An SEA or LEA could evaluate the preparedness of its high school graduates for postsecondary education by designating the postsecondary institution as its authorized representative through a written agreement. The SEA/LEA could then obtain information such as remedial courses their graduates had to take in college, or how long their graduates persisted in college.
- State or Federally-funded early childhood education programs could obtain information on how well their students performed in kindergarten by designating an SEA or LEA as their authorized representative through a written agreement.

### Protecting Student Privacy

It is important, however, that stewards of education data ensure that students' personal information is properly safeguarded, is used only for legitimate purposes, and is used only when necessary. To help LEAs and SEAs understand their obligations to carry out these activities in a safe, FERPA-compliant way, the Department is publishing: "The Family Educational Rights and Privacy Act: Guidance for Reasonable Methods and Written Agreements." This document, also included as Appendix A to the final regulations, details the specific requirements for written agreements under both the audit and evaluation exception and the studies exception. It also provides best practices for other provisions that could be included in agreements, such as enforceable sanctions permitted under civil law. SEAs and LEAs are required to use "reasonable methods" to ensure to the greatest extent practicable that

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authorized representatives are FERPA-compliant. The document describes best practices for reasonable methods.

Under the new regulations, the Department has stronger, more specific enforcement authority. SEAs and other entities (such as student loan guaranty agencies, student loan lenders or nonprofits) that receive Department funds and violate FERPA (regardless if they have students in attendance) are subject to Departmental enforcement. The type of enforcement action the Department may take will depend upon the circumstances behind the violation, and whether the violating entity receives Department funds. The preamble to the revised regulations provides additional details to clarify what types of enforcement actions are possible under various circumstances.

SEAs' and LEAs' responsibilities to appropriately protect student personal information extend beyond FERPA. In determining how the new regulations affect your school or district, it is also necessary to consult State and local laws and to consider the best practices for privacy, confidentiality, and data security.

### Ensuring the Safety of Students

#### *Changes to the Directory Information exception*

As in the past, if an LEA or school has a policy of disclosing directory information, it must give public notice to parents and eligible students of the types of information designated as directory information, and give them the right to opt out. The Department encourages LEAs and schools to properly designate directory information, as these designations make it easier to engage in mundane activities such as publishing yearbooks or creating graduation programs.

The revised regulations permit LEAs and schools to adopt limited directory information policies that allow the disclosure of directory information to specific parties, for specific purposes, or both. It is up to individual LEAs and schools to decide whether to adopt limited directory information policies and how to implement them.

- The Department has also changed the directory information exception to make clear that parents and eligible students may not, by opting out of directory information, prevent an LEA or school from requiring a student to wear or present a student ID or badge. The Department is not requiring LEAs or schools to establish policies mandating that students wear badges; these are individual decisions that LEAs and schools should make taking into account local circumstances.

### Providing Technical Assistance to SEAs and LEAs

We recognize that SEAs and LEAs will need guidance to comply with the new FERPA regulations. The Department's Privacy Technical Assistance Center is available to SEAs and LEAs as the one-stop shop for technical assistance on the applicability of FERPA to State longitudinal data systems; how to use education data to assess program effectiveness, while protecting privacy and remaining FERPA-compliant; and various other best practices for data security and governance. PTAC coordinates all of its FERPA-related work with the Department's Family Policy Compliance Office (FPCO)<sup>1</sup>. This allows those

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<sup>1</sup> FPCO is the office designated by the Secretary of Education to carry out the administration of FERPA. FPCO also provides guidance to the field on FERPA, as well as handles the enforcement of the law, including the investigation of complaints by parents and students. To ease the burden of States and districts for contacting the Department on FERPA or other data security and confidentiality issues, we created PTAC. Questions on FERPA submitted to PTAC are vetted through FPCO. FPCO can be contacted directly at 1-800-872-5327 or <http://www.ed.gov/fpc>.

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seeking assistance from the Department on FERPA to get the benefit of the technical expertise of our FERPA-experts, with the ease of contacting the one-stop shop. If you would like technical assistance on this area of the law, or more information about the best practices for privacy, confidentiality, and data security, please contact PTAC at [PrivacyTA@ed.gov](mailto:PrivacyTA@ed.gov) or Toll-Free Phone: 855-249-3072.

We are planning a series of FERPA webinars for SEAs and LEAs. The first two webinars are:

- December 7, 2:00 EST "FERPA 101: Basic FERPA for LEAs"
- January 11, 2:00 EST "Data Sharing Under the New FERPA Regulations"

Please check the PTAC website for additional webinars in February and March dealing with FERPA considerations for post secondary institutions and FERPA in the context of special education.

The Department has made a number of guidance documents available on the PTAC website at <http://nces.ed.gov/programs/ptac/>, including:

- "The Family Educational Rights and Privacy Act: Guidance for Reasonable Methods and Written Agreements"
- Updated model FERPA notifications
- "Data Governance Checklist"
- "Data Governance and Stewardship"
- "Data Security Checklist"
- "Data Security Top Threats to Data Protection"
- "Responding to IT Security Audits"
- "Data Security and Management Training: Best Practice Considerations"

Finally, the National Center for Education Statistics (NCES) issued the following four technical briefs for comment to further the national conversation on the best practices for data security and privacy. Based on comments received, we intend to re-issue the first two in early 2012 with only minor modifications as formal ED non-regulatory guidance documents. The third document will be revised and reissued as formal ED non-regulatory guidance later in 2012 after the Department has secured more public input. To submit comments on the briefs please email [PrivacyTA@ed.gov](mailto:PrivacyTA@ed.gov).

- NCES Technical Brief 1: "[Basic Concepts and Definitions for Privacy and Confidentiality in Student Education Records](#)"
- NCES Technical Brief 2: "[Data Stewardship: Managing Personally Identifiable Information in Student Education Records](#)"
- NCES Technical Brief 3: "[Statistical Methods for Protecting Personally Identifiable Information in Aggregate Reporting](#)"

The public puts its trust in the stewards of education data to ensure students' personal information is properly safeguarded and is used only for legitimate purposes and only when absolutely necessary. The Department deeply values this trust and strives to ensure it is doing all it can do to protect the privacy of our students as the uses of their data to improve education increase.

For more information about FERPA, please see the Family Policy Compliance Office Web site: [www.ed.gov/fpco](http://www.ed.gov/fpco).

To access the final regulations please visit [www.federalregister.gov](http://www.federalregister.gov).



# First Look: New FERPA Regulations

Thaddeus Ferber and Danielle Evennou

December 2, 2011

People and organizations who've been frustrated by severe restrictions on sharing data about young people received some relief from new guidance on FERPA released yesterday by the U.S. Department of Education.

What is FERPA and why does it matter?

Ensuring that young people are ready for college, work and life requires a number of institutions, systems and organizations to work together. To do so with precision, community leaders need rigorous data which crosses departmental lines to hold decision-makers collectively accountable for results.

A leading reason they don't have the interagency data they need is FERPA: the Family Educational Rights and Privacy Act (FERPA). This Act, passed before the days of the Internet, inadvertently prevents data from being used in common sense ways to help ensure that programs for young people are efficient and effective.

Too often, instead of pooling resources and developing one effective data and accountability system, communities and states are faced with redundant technological expenditures, overlapping or missing sets of information, and cumbersome (if not impossible) transfer of data. Consequently, most community leaders and service providers still do not have the information they need to be effective despite having new resources to build and improve data systems.

FERPA, along with the Health Insurance Portability and Accountability Act (HIPAA), are the biggest obstacles communities and states face when trying to implement a data system which that works.

This is why the Forum has been working to get these policies changed.

The new FERPA regulations are an important step in the right direction. A true fix, which would complete the work of allowing all relevant departments to share information and would allow the information to be used for commonsense purposes, will require congressional action.

## Analysis of the New Regulations

### No Changes on For What Purposes the Data Can Be Used, But Important Changes on Who is Allowed to Share Information

We have focused in on two key questions governed by FERPA: **Who is allowed to share information, and for what purposes are they are allowed to use that information?**

There are no significant changes regarding for what purposes the data can be used. In both the old and new FERPA regulations, the data can be used only for "audit or evaluation, or any compliance or enforcement activity in connection with Federal legal requirements that relate to these programs."

The new guidance from the Department of Education does make significant changes to who is allowed to share information. Interestingly, the *regulations allow more agencies to share data on children aged 0-6 than they allow for children 7 and older.*

FERPA regulations state that "educational agencies and institutions are permitted to nonconsensually disclose Personally Identifiable Information (PII) to 'authorized representatives' of State and local educational authorities, the Secretary, the Attorney General of the United States, and the Comptroller General of the United States, as may be necessary in connection with the audit, evaluation, or the enforcement of Federal legal requirements related to

Federal or State supported education programs.”

So the key question becomes, who are the “authorized representatives” who are allowed to share the data? As the department pointed out in its notice of proposed rulemaking, the previous interpretation of FERPA was that authorized representatives “does not include other State or Federal agencies because these agencies are not under the direct control (e.g., they are not employees or contractors) of a State educational authority.” Under this interpretation, “an SEA or other State educational authority may not make further disclosures of PII to other State agencies, such as State health and human services departments, because these agencies are not employees or contractors to which the State educational authority has outsourced the audit or evaluation of education programs (or other institutional services or functions).”

The new guidance rescinds this restrictive interpretation. It defines an authorized representative as “any entity or individual designated by a State or local educational authority or an agency headed by an official listed in §99.31(a)(3) who is involved in Federal- or State-supported education programs.”

This means that state and local education authorities are now allowed to share data with other government agencies that are not under their direct control, as long as those other agencies are involved in federal or state-supported education program.

So the next question becomes, what is meant by an “education program”? Does that just mean schools?

The new guidance anticipates this question, and provides the following definition: “any program that is principally engaged in the provision of education, including, but not limited to, early childhood education, elementary and secondary education, postsecondary education, special education, job training, career and technical education, and adult education, and any program that is administered by an educational agency or institution.”

This provides greater flexibility than before, signaling that “education program” means more than just schools. But it could, and should, have gone farther. In fact, for early childhood programs it did go farther, much to its credit. The new guidance defines an early childhood education program as one that, in part, “serves children from birth through age six that addresses the children’s cognitive (including language, early literacy, and early mathematics), social, emotional and physical development).”

### Who is Allowed to Share Data?

Can you share data with a department not controlled by the state education authority?		
	Old FERPA regulations	New FERPA regulations
Children aged 0-6	No	Yes
Children 7 years and older	No	Yes

Can you share data with an agency running early childhood education programs, postsecondary education programs, special education programs, job training, career and technical education programs, and adult education programs?		
	Old FERPA regulations	New FERPA regulations
Children aged 0-6	No	Yes
Children 7 and older	No	Yes

Can you share data with an agency running programs to improve social, emotional and physical development?		
	Old FERPA regulations	New FERPA regulations
Children aged 0-6	No	Yes
Children 7 and older	No	No

## Understanding the Department of Education's Intent

In addition to the handful of pages detailing the specific changes to the regulation itself, the Department of Education also released hundreds of pages about its rationale for making the changes, the comments it received from the public regarding the proposed changes and its response to those comments.

Our take on these accompanying documents is that they strongly suggest that Department of Education supports interagency data sharing, and that it would likely be supportive of such efforts by states and localities.

In this section, we provide selected excerpts from the accompanying materials which support interagency data sharing.

### Excerpts from the Notice of Proposed Rulemaking

- The new guidance goes as far as explicitly stating that “there is no reason why a State health and human services or labor department, for example, should be precluded from serving as the authority's authorized representative and receiving non-consensual disclosures of PII to link education, workforce, health, family services, and other data for the purpose of evaluating, auditing, or enforcing Federal legal requirements related to, Federal or State supported education programs.”

### Excerpts from the Public Comments Submitted to the Department

- Supporters of the proposed regulations noted that, by reducing barriers to data sharing, more States would be able to connect their data systems to drive improvement in K-12 schools. Commenters noted several specific evaluations that would be possible with the proposed amendments to the audit or evaluation exception. For example, an evaluation of college freshmen, who all graduated from the same high school, may reveal the students needed postsecondary remediation in math. This information could help the high school improve its math program. Likewise, career and technical education (CTE) agencies would be able to improve program effectiveness by accessing more data with their collaborative partners in workforce development and other non-educational agencies that prepare students for college and careers.
- Many commenters were supportive of the proposal to define the term “education program.” Many of these commenters commended the Department’s proposal to adopt a broad definition of “education program” because doing so recognizes the fact that education begins prior to kindergarten and involves programs not administered by State or local educational agencies.
- While some commenters expressed concern that an overly broad definition of “education program” would result in extraneous programs being wrongly allowed access to student PII from education records, others expressed concern that an overly narrow definition would hinder legitimate data sharing needed to improve education programs. One commenter was concerned that the definition would omit programs many believe are necessary for students to succeed but may not be “principally engaged in the provision of education.” The commenter gave several examples including substance abuse, anti-bullying, and suicide prevention programs. Numerous commenters provided other examples of specific programs and asked the Department to identify if those programs would be considered an education program under the proposed definition.
- Commenters specifically requested clarity about what types of early childhood programs would be considered education programs. A few commenters suggested that the Department utilize the HEA definition of “early childhood education program.” One commenter suggested that we change “principally” to “primarily” in the definition of “education program.” Another recommended that the definition include “transitions from secondary to postsecondary education.” We also received the suggestion that we amend the definition of “education program” to specify that the program must be principally engaged in the provision of education to students in early childhood through postsecondary.

## Excerpts from the Department's Responses to the Comments

- The Department has decided to make several changes to the definition as a result of the comments received. Whether a program is determined to be an education program should be based on the totality of the program and not on whether the program contains a specific "incidental educational or training activity within a broader non-education program," as suggested by one commenter.
- The final regulations provide that any program administered by an educational agency or institution is considered to be an education program. We have made this change to ensure that, in addition to programs dedicated to improving academic outcomes, this definition includes programs, such as bullying prevention, cyber-security education, and substance abuse and violence prevention, when administered by an educational agency or institution.
- It is the Department's intent that the following types of programs, regardless of where or by whom they are administered, fall under the new definition of "education program": the educational programs conducted by correctional and juvenile justice facilities or alternative long-term facilities such as hospitals, dropout prevention and recovery programs, afterschool programs dedicated to enhancing the academic achievement of its enrollees, schools for the hearing and visually impaired, college test tutoring services, and high school equivalency programs. The following are examples of the types of programs that will generally be excluded from the definition of "education program": programs that are principally engaged in recreation or entertainment (such as programs designed to teach hunting, boating safety, swimming, or exercise), programs administered by direct marketers, and neighborhood book clubs. These are not all-inclusive lists; each program will need to be assessed to determine if it meets this regulatory definition of "education program" because it is principally engaged in the provision of education.
- While nothing in the final regulations specifically prohibits a State politician or private company, for example, from being designated as an authorized representative, the full requirements under FERPA must be met before PII from education records may be disclosed to any party. These regulations do not expand any of the reasons an individual or an entity can be designated as an authorized representative. As before, it may only be done to conduct an audit, evaluation, or enforcement or compliance activity.
- Some commenters also appear to have misunderstood the Department's previous interpretation of the term "authorized representative" and mistakenly assumed that the Department has historically only permitted employees and contractors of FERPA-permitted entities to serve as authorized representatives. This is not the case. For instance, prior to the issuance of the Hansen Memorandum in 2003, the Department entered into a memorandum of agreement with the Centers for Disease Control and Prevention (CDC) in which the Department designated the CDC to serve as its authorized representative for purposes of collecting information under the Metropolitan Atlanta Developmental Disabilities Surveillance Program.
- The new definition of "education program" helps to ensure that the FERPA regulations do not impede States' ability to comply with ARRA [American Recovery and Reinvestment Act, which called for the creation of State Longitudinal Data Systems]. As discussed in the NPRM [Notice of Proposed Rulemaking], in order to ensure that the Department's regulations do not create obstacles to States' compliance with ARRA, the Department sought to find a solution that would give effect to both FERPA and this more recent legislation by defining the term "education program" to include programs that are not administered by an educational agency or institution."
- In this case, the Department is interpreting its regulations in a manner that is consistent with FERPA, the America COMPETES Act, and ARRA. Under section 6401(e)(2)(D) of the America COMPETES Act, Congress clearly set forth its desire that States develop SLDS that cover students from preschool through postsecondary education by including information such as "the capacity to communicate with higher education data systems," "information regarding the extent to which students transition successfully from secondary school to postsecondary education, including whether students enroll in remedial coursework,"

and “other information determined necessary to address alignment and adequate preparation for success in postsecondary education.”

- The Department’s definition of the term “education program” is intended to facilitate the disclosure of PII [Personally Identifiable Information] from education records, as necessary, to evaluate a broad category of education programs.”
- We believe that the definition of the term “education program” sufficiently recognizes those common elements among entities that need to evaluate education programs and services, regardless of whether the education programs are funded by the Department.

## Conclusion

Our work is not done.

We remain hopeful that the Department of Education will allow data sharing with agencies running programs to improve social, emotional and physical development for young people older than 6, the same way it now does for agencies running programs for children 6 and younger.

Beyond that, more complete flexibility would likely require action by Congress, not just the administration. We look forward to working with Congress to ensure that the necessary changes are made.

There can be no doubt, however, that today there is one less bureaucratic hurdle standing in the way of community efforts to hold departments and institutions collectively accountable for achieving results.

## HIPAA Updates

- The Privacy Rule – establishes patients' privacy rights and addresses the use and disclosure of protected health information ("PHI") by covered entities and business associates
- Goal of the Privacy Rule
  - One major goal is to ensure that individuals' PHI is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well being.
  - The Privacy Rule strikes a balance that permits important uses of information while protecting the privacy of people who seek care.
- PHI is health information created or received by a Covered Entity that:
  - **Identifies** an individual (or contains enough information to reasonably identify an individual)
  - **Relates to** an individual's past, present, or future health (mental or physical), healthcare treatment, or payment for healthcare
  - Is **maintained or disclosed** in any form or medium
    - Electronic data
    - Paper or other hard copies of data
    - Oral transmission of information
  - Can include:
    - Encounter/visit documentation
    - Lab Results
    - Appointment dates/times
    - Invoices
    - Radiology films and reports
    - History and Physicals (H&Ps), etc.
    - Patient identifiers (Names, SSNs, birthdates, phone #s)
- HIPAA gives an individual certain rights with respect to his or her PHI. These rights include:
  - Right to access, inspect, and copy
  - Right to request an amendment
  - Right to an accounting of disclosures
- The Security Rule – establishes requirements for protecting electronic PHI
- The Breach Notification Rule – requires HIPAA covered entities and their business associates to provide notification following a breach of unsecured PHI
- The Enforcement Rule – establishes both civil monetary penalties and federal criminal penalties for the knowing use or disclosure of PHI in violation of HIPAA

## The HITECH Act is the "Health Information Technology for Economic and Clinical Health Act of 2009"

- Key changes to HIPAA in these areas:
    - Additional rights of individuals with regard to their PHI
    - Additional restrictions on certain disclosures
    - Direct statutory liability for business associates
    - Increased civil penalties and expanded criminal liability
-

- Uncorrected willful neglect (\$50K per violation/\$1.5M max)
  - Civil and criminal liability for HIPAA violations extended to business associates
  - Mandatory investigations and civil penalties for violations due to willful neglect
- Increased emphasis and significant funding on enforcement

First Judgments with Penalties under the Reg include:

#### **Cignet (PG County, MD)**

- The first-ever civil money penalty of \$4.3 million
- Cignet violated 41 patients' rights by denying them access to their medical records when requested between September 2008 and October 2009.
- The HIPAA Privacy Rule requires that a covered entity provide a patient with a copy of their medical records within 30 (and no later than 60) days of the patient's request.
- The CMP for these violations is \$1.3 million.
- Cignet failed to cooperate with OCR's investigations of the complaints and produce the records in response to OCR's subpoena.
- Covered entities are required under law to cooperate with the Department's investigations.
- The CMP for these violations is \$3 million.<sup>1</sup>

*"Covered entities and business associates must uphold their responsibility to provide patients with access to their medical records, and adhere closely to all of HIPAA's requirements . . . The U.S. Department of Health and Human Services will continue to investigate and take action against those organizations that knowingly disregard their obligations under these rules."*

-OCR Director Georgina Verdugo

<http://www.hhs.gov/ocr/privacy/hipaa/enforcement/examples/cignetre>

#### **Mass General—"The Million Dollar Subway Ride," February 14, 2011**

- An employee of General Hospital Corporation and Massachusetts General Physicians Organization Inc. ("Mass General") left documents on a subway that included a patient schedule containing protected health information ("PHI") of 192 patients, and billing forms with PHI for 66 of those patients. This included PHI of patients with HIV/AIDS.
- The records were bound only by a rubber band!
- Mass General paid the US Government a \$1,000,000 settlement and entered into a Corrective Action Plan ("CAP"):
  - Develop and implement a comprehensive set of policies and procedures that ensure PHI is protected when removed from Mass General's premises;
  - Train workforce members on these policies and procedures; and
  - Designate the Director of Internal Audit Services to serve as an internal monitor who will conduct assessments compliance with the CAP and render semi-annual reports to HHS for a 3-year period.

#### **UCLA Health System - July 6, 2011**

- Settlement of \$865,500 and corrective action plan.
- Followed from complaints by two different celebrities about improper access to health records. (Brittany Spears and Maria Shriver?)
- Furthermore, an investigation found that unauthorized employees repeatedly looked at other UCLAHS patient records from 2005- 2008.

### **HIPAA Enforcement**

To boost enforcement of the HIPAA security rule, OCR has added investigators in 10 regional offices. HHS is seeking \$5.6 million increase in funding for Fiscal 2012 enforcement.

In FY 2010, the office received approximately 9,400 complaints associated with HIPAA privacy and security rules

HIPAA and its implementing regulations place constraints on the release of individually identifiable “protected health information” by health care providers to litigants. Citation: 45 C.F.R. 164.512(e)

HIPAA does not permit health care providers to respond to “a subpoena, discovery request, or other lawful process that is not accompanied by an order of court or administrative tribunal” unless the health care provider “receives satisfactory assurance . . . from the party seeking the information” of “reasonable efforts” to (i) provide appropriate notice to the affected patient or (ii) secure a qualified protective order. Citation: 45 C.F.R. 164.512(e)

### **When HIPAA doesn't apply**

- When PHI is received as a result of an authorization or subpoena  
But . . .
- State law may apply
  - Common law liability principles may apply
  - Professional ethics rules may apply