

Module 12

Access to and Examination of Records



*This module was developed
in collaboration by:*

The U.S. Department of Education,
Office of Special Education and
Rehabilitative Services (OSERS),
Office of Special Education
Programs (OSEP) |
*Frank Miller**

OSERS' Office of Policy and Planning |
Mary Louise Dirrigl and Jessica Spataro

The U.S. Department of Education,
Office of the General Counsel |
Kala Surprenant

The National Dissemination Center
for Children with Disabilities (NICHCY) |
Lisa Küpper

Produced by:
National Dissemination Center
for Children with Disabilities

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* As of this publication date, Frank Miller is now with the Department of Education's Family Policy Compliance Office.

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NICHCY Lead: Lisa Küpper

OSEP Lead: Jennifer Simpson

OGC Lead: Kala Surprenant

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<http://www.parentcenterhub.org/repository/legacy-partc/>

Background and Discussion

This module is part of a training curriculum on the Part C regulations of the Individuals with Disabilities Education Act, as amended in 2004. The curriculum provides a detailed discussion of the Part C regulations as published in the *Federal Register* on September 28, 2011.¹

The curriculum is entitled *Building the Legacy for Our Youngest Children with Disabilities*. This module is entitled *Access to and Examination of Records* and is the 12th module in the curriculum.

Please be aware that the information in this module is *not* a substitute for the requirements reflected in the IDEA statute and Part C regulations.

Early Intervention and IDEA

Thanks to a powerful and important federal law called the Individuals with Disabilities Education Act, or IDEA, 336,895 eligible infants and toddlers birth through age 2 received early intervention services in 2011 under Part C of IDEA.²

Early intervention services are concerned with all the basic and brand-new developmental skills that babies typically develop during the first three years of life, such as:

- physical (reaching, rolling, crawling, and walking);
- cognitive (thinking, learning, solving problems);
- communication (talking, listening, understanding);

How the Trainer's Guide is Organized

This trainer's guide is organized by slide. A thumbnail picture of each slide is presented, along with brief instructions as to how the slide operates. This is followed by a discussion intended to provide trainers with background information about what's on the slide. Any or all of this information might be appropriate to share with an audience, but that decision is left up to trainers.

- social/emotional (playing, feeling secure and happy); or
- adaptive behavior (eating, dressing).³



Record-Keeping in Early Intervention

In delivering services to infants and toddlers and their families under Part C of the IDEA, the lead

agency and its early intervention service (EIS) providers collect information about the infant or toddler and his or her family. This includes personally identifiable information. As we all know from recent "security" breaches,⁵ there are many reasons to protect personally identifiable information (PII) and to take care in how PII is handled. Who can legitimately access our personal records, for example, and to whom may our records be legally disclosed with or without our consent?

This module provides an overview of how the early intervention records of children

Early intervention services are designed to meet the needs of eligible infants and toddlers who have a *developmental delay* or *disability*. Services may also address the needs and priorities of each child's family, to help family members understand the special needs of the child and how to enhance his or her development.⁴

What's a Lead Agency?

Each State has one State-level public agency that is designated by the Governor to be responsible for developing and implementing the early intervention system in the State. The agency may vary from State to State, but it's referred to in IDEA as the "lead agency." We'll do the same in this module.

Trainer's Note

Throughout this training module, all references in the discussion section for a slide are provided at the *end* of that slide's discussion.



and families are subject to privacy protections under federal laws, including IDEA 2004 and the Part C regulations found at 34 CFR Part 303. This module focuses on a parent's rights to access and examine those records.



This Module in the Part C Training Curriculum

The training curriculum on Part C of IDEA is organized into separate themes, which multiple training modules under most themes. The themes are:

Theme A | Welcome to IDEA

Theme B | Public Awareness Program and the Child Find System

Theme C | Evaluating Infants and Toddlers for Disabilities (Post-Referral Activities)

Theme D | Individualized Family Service Plan (IFSP)

Theme E | Transition from Part C to Part B of IDEA

Theme F | Procedural Safeguards

Theme G | Use of Funds

This module falls within the umbrella topic of **Theme F, Procedural Safeguards**. Four modules were originally planned as part of Theme F, but in the end, only two (listed below) were finalized and published:

- *Introduction to Procedural Safeguards* (Module 10), which introduces the purposes of Part C's procedural safeguards and provides a brief overview of specific safeguards such as prior written notice, the procedural safeguards notice, and confidentiality of personally identifiable information; and

- *Access to and Examination of Records* (this module), which examines in detail the procedural safeguards that guarantee parents have the right to inspect and review their infant or toddler's early intervention records, as well as the right to ask that inaccurate or misleading records be amended.

For Whom Is This Module Designed?

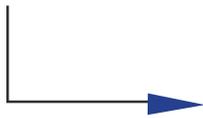
This module is primarily intended for trainers to use with audiences who are newcomers to the law, the early intervention process, and especially requirements associated with the keeping and maintaining of children's early intervention records. This includes:

- parents and family members of an infant or toddler who has, or is suspected to have, a developmental delay or a disability;
- early intervention and early childhood professional candidates who are learning about Part C early intervention programs for our youngest children with disabilities and the importance of maintaining the privacy of children's early intervention records;
- other stakeholders in the early childhood community, including Head Start and Early Head Start personnel, preschool professionals, and early childhood educators;
- new staff, advocates, policy makers, administrators, and early childhood specialists who will be working with either the Part C system or with infants and toddlers who have disabilities and their families, but who have limited knowledge of what the law requires in terms of protecting the rights and privacy of children and families; and
- staff of Parent Training and Information (PTI) centers and of Community Parent Resource Centers (CPRCs), as well as other organizations serving families of children who have disabilities.

Files You'll Need for This Module

- **Trainer Guide.** The trainer guide describes how the slides operate and explains the content of each slide, including relevant requirements of the statute passed by Congress in December 2004 and the final regulations for Part C published in September 2011. The trainer guide is available in PDF and Word® formats.
- **Slideshow.** We are pleased to provide a slideshow (produced in PowerPoint®) around which trainers can frame their presentations and training on parents' right to access and examine the early intervention records of their infant or toddler with a disability. You do NOT need the PowerPoint® software to use the slideshow. The presentation is saved as a "show"—which means it will launch when you open it.
- **Handouts for Participants.** The following handouts are available:
 - Handout 14 | Part C's Confidentiality Provisions: Summary of Key Points
 - Handout 15 | Part C's Confidentiality Provisions: Verbatim Regulations
- **Activity Sheet 15 (optional).** This activity sheet is provided as a closing activity to the training session and can be used to review the module's content.
- **Speaker Notes.** Provided as a Word file, the Speaker Notes show thumbnail pictures of all slides in the presentation, with lines next to each for you to annotate your presentation, if you wish. You can also share the Speaker Notes with participants.

All files can be downloaded free of charge from the website of the Center for Parent Information and Resources



<http://www.parentcenterhub.org/repository/partc-module12/>

References & Footnotes

- ¹ U.S. Department of Education. (2011, September 28). Early intervention program for infants and toddlers with disabilities: Rules and regulations. *Federal Register*, 76(188), 60140-60309. Washington, DC: Office of Special Education and Rehabilitative Services, Department of Education. Online at: <http://www.gpo.gov/fdsys/pkg/FR-2011-09-28/pdf/2011-22783.pdf>
- ² Technical Assistance Coordination Center. (2012). *Historical state-level IDEA data files: Part C child count 2011*. Retrieved November 11, 2013, from: <http://uploads.tadnet.org/centers/97/assets/2414/download>
- ³ Center for Parent Information and Resources. (2014, March). *Overview of early intervention*. Washington, DC: NICHCY. Online at: <http://www.parentcenterhub.org/repository/ei-overview/>
- ⁴ §303.13(b)(3) of the Part C regulations.
- ⁵ Identity Theft Resource Center. (2015, January). *Identity Theft Resource Center breach report hits record high in 2014*. San Diego, CA: Author. Online at: <http://www.idtheftcenter.org/IIRC-Surveys-Studies/2014databreaches.html>



Looking for IDEA 2004?

Visit the Center for Parent Information and Resources' website, where you can download copies of:

- IDEA's statute (the law passed by Congress in 2004)
- Part C regulations (published by the U.S. Department of Education on September 28, 2011)
- Part B regulations (published by the U.S. Department of Education on August 14, 2006 and modified on February 12, 2013)

Find all at: <http://www.parentcenterhub.org/repository/idea-copies/>

Finding Specific Sections of the Regulations: 34 CFR

As you read the explanations about the Part C regulations, you will find references to specific sections, such as §303.21. (The symbol § means "Section.") These references can be used to locate the precise sections in the Part C regulations that address the issue being discussed. In most instances, we've also provided the verbatim text of the Part C regulations so that you don't have to go looking for them.

The Part C regulations are codified in Title 34 of the *Code of Federal Regulations*. This is more commonly referred to as 34 CFR or 34 C.F.R. It's not unusual to see references to specific sections of IDEA's regulations include this—such as 34 CFR §303.21, which is where you'd find Part C's definition of "infant or toddler with a disability." We have omitted the 34 CFR in this training curriculum for ease of reading.

Citing the Regulations in This Training Curriculum

You'll be seeing a lot of citations in this module—and all the other modules, too!—that look like this: 76 Fed. Reg. at 60250

This means that whatever is being quoted may be found in the *Federal Register* published on September 28, 2011—Volume 76, Number 188, to be precise. The number at the end of the citation (in our example, 60250) refers to the page number on which the quotation appears in that volume. Where can you find Volume 76 of the *Federal Register*? At this address:

<http://www.gpo.gov/fdsys/pkg/FR-2011-09-28/pdf/2011-22783.pdf>

Module 12



Access to & Examination of Records

How to Operate the Slide:

Slide loads fully. No clicks are necessary except to advance to the next slide.

CLICK to advance to next slide.

Use this slide to introduce your audience to what this training will be about: Parental rights to have access to, and to examine, the early intervention records of their infant or toddler in the Part C program.

How is This Subject Relevant to the Audience?

While you can use the title slide to introduce the training session and simply move on to the next slide, you might also take a moment to see how this topic relates personally and professionally to members of the audience. Activating participants' connections to the topic can help bring the training to life for them individually, and the actions of raising hands and offering up answers engages them on a physical level. You might ask questions such as:

- How many of you have a child receiving early intervention services right now? (Show of hands.)

- How many of you have had a child receive early intervention services in the past? (Show of hands.)
- How many of you work in the early intervention system and contribute information that gets put into the records of a child or children receiving early intervention services? (Show of hands.)
- What kind of information do you suppose is included in a child's early intervention records? (Participants can call out their suggestions, which you might jot on a flipchart.)

This step shouldn't last long. Plunge into the content!

Modules on Part C's Procedural Safeguards



Introduction to
Procedural Safeguards

Access to & Examination
of Records

Slide loads completely. No clicks are necessary except to advance to the next slide.

CLICK to advance to next slide.

Slide 2 provides the audience with the bigger picture of this module within a theme in the *Building the Legacy for Our Youngest Children* training curriculum. Indicate that:

- There are 10 training modules in the curriculum.
- These modules are divided up into 6 major themes in early intervention.
- Other themes focus on topics such as the evaluation and assessment process in early intervention or the individualized family service plan (IFSP) that must be written for every infant or toddler who is determined eligible for IDEA Part C services.
- This module falls under the theme of Procedural Safeguards.
- There are 2 modules total under that theme, which participants can see listed on the slide.

- Participants might think of procedural safeguards as the umbrella that protects the rights of families and children in Part C, which is why the picture on the slide is of a woman well-protected under an umbrella.

Do Participants Need More Information on Procedural Safeguards?

Depending on the prior knowledge and experience of participants with early intervention, you may wish to elaborate on the broader subject of procedural safeguards. As appropriate, you might mention such facts as:

Procedural safeguards are an important part of the Part C regulations and IDEA itself. The term "safeguards" is revealing in and of itself, because that's the purpose behind them—to protect (safeguard) parents' and children's rights within the early intervention system.

Parent rights touch upon many aspects of participating in Part C:

- the right to participate in meetings about their child;
- the right to participate in developing and reviewing the IFSP of their child;
- the right to give or refuse consent to particular actions or requests of the early intervention system;

- the right to examine their child’s early intervention records (the subject of this module);
- the right to disagree and be heard by an impartial third party; and
- much more.

For more information about the procedural safeguards under Part C—what they are and where to find them in the regulations—see the list in the box, *Procedural Safeguards at a Glance*.



Procedural Safeguards at a Glance

Part C’s procedural safeguards can be found in the regulations in Subpart E. Within Subpart E are the following subsections:

General | §303.400

Confidentiality of Personally Identifiable Information and Early Intervention Records | §303.401—§303.417

Parental Consent and Notice | §303.420—§303.421

Surrogate Parents | §303.422

Dispute Resolution Options | §303.430

Mediation | §303.431

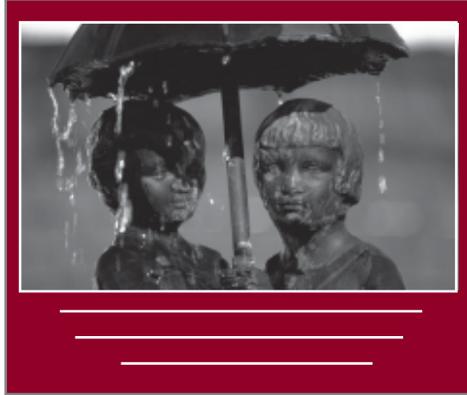
State Complaint Procedures | §303.432—§303.434

States That Choose to Adopt the Part C Due Process Hearing Procedures Under Section 639 of the Act | §303.435—§303.438

States That Choose to Adopt the Part B Due Process Hearing Procedures Under Section 615 of the Act | §303.440—§303.449

This module looks at:**Parental right to:**

- Inspect & review their child's early intervention records
- Ask that the records be amended
- Request a hearing to challenge information in their child's record



Slide loads completely. No clicks are necessary except to advance to the next slide.

CLICK to advance to next slide.

Slide 3 is an advance organizer for the audience, to alert them to the areas covered in this training module and, hopefully, what they'll learn. Again, they can see that the picture on the slide shows two children standing under an umbrella, reinforcing the concept of the umbrella of protection that the procedural safeguards (including the parental rights listed on the slide) bring to families and children in Part C.

Suggestions for Quick Opening Activities

Any of the following suggestions would take about 1-2 minutes. You can expand each to 5 minutes by having participants then call out what their "partners" told them and jotting these down on a flipchart.

Suggestion 1 | Ask participants to introduce themselves to the person seated next to (or behind) them and exchange two pieces of information: (a) one thing they already know about the topic, and (b) one thing they hope to learn about the topic.

Suggestion 2 | Ask participants to stand up and politely bow to two or three people nearby, asking them why they are here today, taking this training on access to (and examination of) records, and what they hope to take away from it.

Suggestion 3 | Ask participants to shake hands with one neighbor and tell that person how this topic relates to their personal or professional life.

Quick Summary of Confidentiality Provisions



- Parents have the right to confidentiality of **personally identifiable information**
- Participating **agencies must comply** with Part C's confidentiality provisions and the State's policies
- All people collecting or using PII in Part C must receive **training** or instruction re: State's confidentiality policies

Opening View:

Slide loads with the header, the photo of the woman, and the 1st bullet.

Click 1:
Bullets 2 and 3 appear.

CLICK AGAIN to advance to next slide.

Slide 4: Background and Discussion

I Click

Pertinent Handouts:

- Handout 14, Summary of Key Points about Confidentiality

Before we actually get into the parents' right to access and examine the early intervention records of their infant or toddler, there's a foundation to be laid about confidentiality of personally identifiable information—otherwise referred to as PII.

So—time for a quick summary about confidentiality in Part C. Much of this information is provided on **Handout 14**.

Summary Points

- Use the three points on the slide and the information below to provide a quick summary of Part C's confidentiality provisions. Make sure you explain what a "participating agency" is, because the term is going to come up again.

- Most participants will probably have an understanding of what constitutes personally identifiable information, given our modern concerns with protecting our individual privacy. Worries about "identity theft" have made many of us aware of certain elements of PII, such as name and social security number.
- The State must have policies and procedures with respect to the protection of PII in its early intervention programs. These policies will be based, at a minimum, on Part C's regulations and requirements.
- The State's policies and procedures will also provide for the training or instruction of all people and agencies that collect or use PII in Part C.

- When a child is first referred to Part C, the lead agency must provide parents with notice that fully informs them about the State’s procedures for complying with Part C’s confidentiality requirements.

Now, for a bit more detail. As needed, pull upon the discussion below to expand the summary of confidentiality.



and Accountability Act, which has three major rules. Its privacy rule protects the privacy of specific “protected health information.”

- Another excellent example of privacy legislation is FERPA, the Family Educational Rights and Privacy Act. FERPA is a federal law that protects the privacy of student education records (more on this later).

Personally Identifiable Information

At the heart and core of confidentiality provisions in Part C of IDEA is the **protection of personally identifiable information**. When a parent brings a baby or toddler to the early intervention system, the information that’s collected about the child and family must be kept confidential. How it can be shared, and with whom, is specified in the Part C regulations and in State policies and procedures.

For how long must the confidentiality of a child’s or family’s personally identifiable information be maintained? | The regulations are very clear about the timeframe across which Part C’s confidentiality procedures are required—“from the point in time when the child is referred for early intervention services under this part until the later of when the participating agency is no longer required to maintain or no longer maintains that information under applicable Federal and State laws.”⁶ More will be said about this on Slide 12.

Privacy requirements in other laws | Maintaining the confidentiality of PII isn’t limited to Part C, of course. The requirement exists in Part B of IDEA as well (in fact, until the 2011 Part C regulations, Part C cross-referenced Part B’s confidentiality requirements). Confidentiality of PII is also a requirement in many federal and State laws.

- Ask participants if they’ve been to the doctor recently and had to sign forms acknowledging they’ve received notice of the HIPAA privacy rule.⁷ HIPAA is the Health Insurance Portability



Brainstorm a list | You can build on this prior knowledge by brainstorming with your audience and generating a quick list of what types of personal information, if released, would allow others to identify the person in question. In the case of early intervention records, we’re talking about being able to identify a given infant or toddler in Part C and his or her family.

“Personally identifiable information” in Part C can be understood as information that can be used to distinguish or trace a child’s identity, such as:

- the child’s name;
- the name of the child’s parent or other family members;
- the child or family’s address;
- a personal identifier, such as the child’s social security number or biometric record;⁸
- other indirect identifiers (such as the child’s date and place of birth, and mother’s maiden name); and
- other information that, alone or in combination, is linked or linkable to a specific child that would allow a reasonable person in the EIS provider community, who does not have personal knowledge of the relevant circumstances, to identify the child with reasonable certainty.⁹

Part C and Confidentiality Provisions in FERPA

As mentioned, FERPA stands for the Family Educational Rights and Privacy Act, federal legislation that protects the privacy of student education records. Its provisions have been adapted for Part C and incorporated into Part C's regulations.

In fact, Part C's regulations now expressly reference FERPA, its definition of PII, and applicable exceptions. Part C's confidentiality provisions are found in §§303.401 through 303.417. (These are summarized on **Handout 14** and provided verbatim on **Handout 15**.)

Defining "Participating Agency"

The meaning of "participating agency" is important, because it delimits the individuals and agencies who, among other things, must comply with the confidentiality provisions laid out in the Part C regulations and in the State's policies and procedures (Bullet 2 on the slide).¹⁰ These are also the individuals and agencies that must receive training or instruction in the same (Bullet 3).¹¹

The definition of "participating agency" appears at §303.403(c), on **Handout 15**, and in the box at the top right.

Discussing "Participating Agency" | Summary Points

Don't confuse "participating agency" with "lead agency." | The *lead* agency is the agency responsible for implementing the early intervention system in the State and overseeing its quality for children and families and its compliance with IDEA. A *participating* agency is a far broader, less specific term. Many agencies can be considered "participating agencies" in early intervention.

Who is? | Individuals, agencies, entities, and institutions are considered to be "participating agencies" when they collect, maintain, or use PII with respect to a child in Part C. This includes the lead agency, EIS providers, and any individual or entity that provides any Part C services.

Definition of Participating Agency at §303.403(c)

(c) *Participating agency* means any individual, agency, entity, or institution that collects, maintains, or uses personally identifiable information to implement the requirements in Part C of the Act and the regulations in this part with respect to a particular child. A participating agency includes the lead agency and EIS providers and any individual or entity that provides any Part C services (including service coordination, evaluations and assessments, and other Part C services), but does not include primary referral sources, or public agencies (such as the State Medicaid or CHIP program) or private entities (such as private insurance companies) that act solely as funding sources for Part C services.

Who isn't? | Primary referral sources are not considered to be participating agencies. Nor are public agencies or private entities that act solely as a funding source for Part C services. Examples of these latter include the State Medicaid or CHIP program (public agencies) and private insurance companies (private agencies), if these act only as sources of funding for the Part C services a child or family receives.

What's a primary referral source? | In case participants aren't familiar with this term, or can't readily recall who's considered to be a primary referral source, you may wish to offer a brief explanation, such as:

Primary referral sources help the Part C system find and identify infants and toddlers who may need early intervention services because of a disability or developmental delay. We're talking about people who are most likely to be interacting with very young children, who are in a position to notice that a child may have a developmental delay or disability and to make a referral to the Part C system. Who might that be?

For your convenience, the box below cites the list of primary referral sources contained in the Part C regulations at §303.303(c). Can participants name a few? Read the list, as need be. And indicate to participants that **primary referral sources are not considered to be “participating agencies” unless they provide Part C services.**



Who’s Listed as a Primary Referral Source at §303.303(c)?

(c) *Primary referral sources.* As used in this subpart, primary referral sources include—

- (1) Hospitals, including prenatal and postnatal care facilities;
- (2) Physicians;
- (3) Parents, including parents of infants and toddlers;
- (4) Child care programs and early learning programs;
- (5) LEAs and schools;

- (6) Public health facilities;
- (7) Other public health or social service agencies;
- (8) Other clinics and health care providers;
- (9) Public agencies and staff in the child welfare system, including child protective service and foster care;
- (10) Homeless family shelters; and
- (11) Domestic violence shelters and agencies.

References & Footnotes

- ⁶ §303.401(c)(2)—Confidentiality and opportunity to examine records: Applicability and timeframe of procedures.
- ⁷ More information on HIPAA is available at: <http://www.hhs.gov/ocr/privacy/index.html>
- ⁸ §99.3 | FERPA’s definition of *biometric record*. A biometric record permits automatic recognition of a person and includes such things as fingerprints, retina and iris patterns, voiceprints, DNA sequence, facial characteristics, and handwriting.
- ⁹ §99.3 | FERPA’s definition of *personally identifiable information*.
- ¹⁰ §303.401(b)(1)—Confidentiality and opportunity to examine records: Confidentiality procedures.
- ¹¹ §303.415(c)— Safeguards.

Nondisclosure of PII

In general, the State’s lead agency or other participating agency must have the **parent’s consent** before it may disclose PII to any party except participating agencies that are part of the State’s Part C system unless there are specific exceptions that apply, which are enumerated in the IDEA Part C and FERPA statute and regulations.

Access Rights of Parents



Parents must be permitted to—

inspect & review any early intervention records relating to their children

that are collected, maintained, or used by the agency under Part C

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CLICK to advance to next slide.

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

Here, simply stated, is one main point of this training module: the right of parents to inspect and review any early intervention or EI records of their children. That information alone might be sufficient for many audiences, especially if you've planned a brief, summative type of session. Moreover, there will be three slides in all on the "Access Rights of Parents"—this is the first.

For longer, more detailed sessions, consider providing the information presented below.

Defining "Early Intervention Records"

The Part C regulations define the term "early intervention records" at §303.403(b) as follows:

(b) *Early intervention records* mean all records regarding a child that are required to be collected, maintained, or used under Part C of the Act and the regulations in this part.

Participants can see this definition on **Handout 15**.

Quick activity suggestion | What kind of information might a child’s early intervention record contain? If you haven’t already done so earlier in this training session, ask participants to brainstorm a list of the kinds of information they’d expect to be collected about an infant or toddler involved in the Part C system. Do this in the large-group, with participants calling out suggestions and perhaps one designee jotting notes on a flipchart.

Possible answers you might hear: medical records, the intake forms, evaluation results, parents’ contact information, child’s disability, documents completed by early intervention staff, payment records, and so on.

Scope of a Child’s EI Records



Back to the main point of the slide: Parents have the right to inspect and review any and all of their child’s early intervention records—whatever documents, files, forms, or other records the Part C system or participating agencies collect, maintain, or use with respect to that child and family. This includes records related to evaluations and assessments, screening, eligibility determinations, development and implementation of IFSPs, provision of early intervention services, individual complaints involving the child, or any part of the child’s early intervention record.¹²

How are parents to know? | How are parents to know what type of information on their child and family is collected and by whom, let alone where it is maintained or how it’s used? Because the lead agency must tell them. As participants can see on **Handout 15** at §303.404 (also shown in the box below), when the child is referred to Part C, the lead agency must give parents notice that informs them as to (among other things):

- what type of PII is collected about children, how, and by whom;

Reference

¹² §303.401(b)(2)—Confidentiality and opportunity to examine records: Confidentiality procedures.

- how the information will be used;
- the policies and procedures that participating agencies must follow regarding storage, disclosure to third parties, retention, and destruction of PII; and
- all the rights of parents and children regarding this information.

Also, upon request | Further, as participants can see at §303.408 (List of types and locations of information): Each participating agency must provide parents, on request, a list of the types and locations of early intervention records collected, maintained, or used by the agency.

§303.404 Notice to parents.

The lead agency must give notice when a child is referred under Part C of the Act that is adequate to fully inform parents about the requirements in §303.402, including—

(a) A description of the children on whom personally identifiable information is maintained, the types of information sought, the methods the State intends to use in gathering the information (including the sources from whom information is gathered), and the uses to be made of the information;

(b) A summary of the policies and procedures that participating agencies must follow regarding storage, disclosure to third parties, retention, and destruction of personally identifiable information;

(c) A description of all the rights of parents and children regarding this information, including their rights under the Part C confidentiality provisions in §§303.401 through 303.417; and

(d) A description of the extent that the notice is provided in the native languages of the various population groups in the State.

Access Rights of Parents



If a parent asks to inspect & review child's records, the agency must comply—

- without unnecessary delay
- before any meeting about the IFSP or any due process hearing

and *in no case more than 10 days* after the request has been made

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CLICK to advance to next slide.

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)



When parents ask to see their child's early intervention records, how quickly must the participating agency respond to that request? As the slide indicates, the agency must respond without unnecessary delay and before any meeting regarding an IFSP or due process hearing. Bottom line: In no case may the participating agency take more than 10 days to respond after receiving the parents' request. That's 10 *calendar* days.

And that is as clear as it can be. What more needs to be said?

Just a Few Details

Of course there's more to say! There's always more.

In this case, we'd just like to provide you with the authorizing regulations for the points on the slide. Here they come!

§303.405 Access rights.

(a) Each participating agency must permit parents to inspect and review any early intervention records relating to their children that are collected, maintained, or used by the agency under this part. The agency must comply with a parent's request to inspect and review records without unnecessary delay and before any meeting regarding an IFSP, or any hearing pursuant to §§303.430(d) and 303.435 through 303.439, and in no case more than 10 days after the request has been made.

What's "§303.430(d) and §303.435 through 303.439" referring to? | As the slide summarizes, these references correspond to due process hearings to resolve disputes between families and the early intervention system. Applied in this context, it means that, when a parent requests to inspect and review his or her child's early intervention records, and has a pending due process hearing, the agency must comply with the parent's request before the due process hearing. (Similarly, the agency must comply with a parent's request before any meeting regarding the IFSP.)

Participants can find this regulatory provision midway through **Handout 15**.

Slide 7

Access Rights of Parents (Slide 3 of 3)

Access Rights of Parents



The right to inspect & review includes:

- the right to a response from the agency to reasonable requests for **explanations & interpretations** of the early intervention records
- the right to request copies of records*

* if failure to provide those copies would effectively prevent the parent from exercising the right to inspect & review the records

Opening View:
Slide loads with the header and Bullet 1.

Click 1: Bullet 2 loads, the picture changes, and the meaning of the asterisk appears at the bottom.

Slide continues on next page ►

Access Rights of Parents



The right to inspect & review includes:

- the right to a response from the agency to reasonable requests for **explanations & interpretations** of the early intervention records
- the right to request copies of records*
- the right to have a representative of the parent inspect & review the records

Click 2

Click 2: Picture changes again, the asterisked text fades away, and Bullet 3 appears.

CLICK AGAIN to advance to next slide.

Slide 7: Background and Discussion

2 Clicks

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)



Up to this point, we've only talked about the parent's right to inspect and review his or her child's early intervention records. This slide—the last one in the "Access Rights of Parents" series—teases out an important, related point: What does this right mean? What does it include? Exclude? In other words, how far does this right go?

The Part C regulations succinctly provide the boundaries of this parental right, just as summarized on the slide and cited verbatim on Handout 15.

What Part C Regulations Say

The relevant regulation for this point can be found at §303.405(b), directly following the provision that gives parents to right to inspect and review their child's EI records (discussed on the previous slide). See the box on the next page and Handout 15.

§303.405 Access rights.

(a) Each participating agency must permit parents to inspect and review any early intervention records relating to their children that are collected, maintained, or used by the agency under this part. The agency must comply with a parent's request to inspect and review records without unnecessary delay and before any meeting regarding an IFSP, or any hearing pursuant to §§303.430(d) and 303.435 through 303.439, and in no case more than 10 days after the request has been made.

(b) The right to inspect and review early intervention records under this section includes—

(1) The right to a response from the participating agency to reasonable requests for explanations and interpretations of the early intervention records;

(2) The right to request that the participating agency provide copies of the early intervention records containing the information if failure to provide those copies would effectively prevent the parent from exercising the right to inspect and review the records; and

(3) The right to have a representative of the parent inspect and review the early intervention records.

Discussing the Slide

As you can see, what's on the slide comes very nearly verbatim from the regulations. It's also clear as to its meaning and, thus, requires little extra explanation.

Beyond the Slide

There are two points that could have been covered on this slide but, for brevity's sake, weren't. These are listed below.

Fees for copies? | As the slide indicates, parents may ask the participating agency for copies of their child's EI records (if not having the copies would effectively prevent them from exercising their right to inspect and review the records). This begs the question: May the participating agency charge the parent for making copies of the early intervention records? The next slide answers this question.

What the participant agency may presume | We've been looking at the provisions at §303.405, Access rights. There's one we haven't examined (shown in the small box at the right), but you may wish to share with the audience and discuss, as need be. It appears at §303.405(c) and is the last provision in that section. As appropriate, refer participants to **Handout 15**.

This specific provision is a safeguard for the participating agency when it complies with a parent's request to examine his or her child's EI records. It protects the agency against situations where one parent may not have the legal authority to act as a parent but still requests to see the child's EI records.

An agency may presume that the parent *does* have the authority to inspect and review records relating to the child unless the agency has been provided documentation that the parent does not have the authority under applicable State laws governing such matters as guardianship, separation, divorce, custody, and foster care.

One More Point about Parental Access Rights

§303.405(c)

(c) An agency may presume that the parent has authority to inspect and review records relating to his or her child unless the agency has been provided documentation that the parent does not have the authority under applicable State laws governing such matters as custody, foster care, guardianship, separation, and divorce.

Fees for Records



The agency:

- **may** charge a fee for copies of records made for parents*

* if the fee does not effectively prevent the parents from exercising their right to inspect & review those records

Opening View

Slide loads with the header "Fees for Records," the 1st bullet, and the meaning of the asterisk toward the bottom.

Fees for Records



The agency:

- **may** charge a fee for copies of records made for parents*
- **may not** charge a fee to search for or retrieve this information
- **must** provide—at no cost to parents—a copy of each evaluation, assessment, & IFSP as soon as possible after each IFSP meeting

CLICKS 1-2

Click 1: Picture changes, Bullet 2 appears, and the asterisked information disappears.

Click 2: Picture changes, and Bullet 3 appears.

CLICK AGAIN to advance to next slide.

See discussion on next page ►



Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

May a participating agency charge the parents for making copies of their child’s early intervention records, or for search for or retrieving the records? When must the participating agency provide a child’s EI records or parts of those records free of charge? These are the questions addressed by this slide.

Summary Answers

May a participating agency charge parents for making copies of their child’s EI records? | Yes, it may, with two conditions.

- If charging a fee would effectively keep the parents from exercising their right to inspect and review their child’s EI records, then the agency may not charge a fee. This protects the right of parents (especially low-income parents and those with limited means) to access their child’s EI records.
- There are times when the participating agency must provide the child’s EI records (or parts thereof) to parents free of charge. The 3rd bullet

on the slide describes such a time—namely, after an IFSP meeting. Documents such as copies of each assessment, evaluation, and IFSP must be given to parents as soon as possible after an IFSP meeting and at no charge.

It should be noted that this latter condition is a bit different from when parents request copies of records. Providing parents with copies of such key documents after an IFSP meeting is a *given*, not a response to a parent’s request.

What about charging fees for finding the records? | No. The participating agency may not charge parents any fees to search for or retrieve the EI records parents have requested to inspect, review, or have copied.

What the Part C Regulations Say, Verbatim

Where, in the regulations, are these basic requirements stated? At §303.409 (Fees for records), provided on **Handout 15** and in the box below. As you can see, the text on the slide comes nearly verbatim from the regulations.



303.409 Fees for records.

(a) Each participating agency may charge a fee for copies of records that are made for parents under this part if the fee does not effectively prevent the parents from exercising their right to inspect and review those records, except as provided in paragraph (c) of this section.

(b) A participating agency may not charge a fee to search for or to retrieve information under this part.

(c) A participating agency must provide at no cost to parents, a copy of each evaluation, assessment of the child, family assessment, and IFSP as soon as possible after each IFSP meeting.

Amending the Records at Parent Request

If a **parent** who believes that information in the early intervention records is...



- inaccurate;
- misleading; or
- violates the privacy or other rights of the child or parent

...the **parent** may request that the agency maintaining the information **amend it**

Slide loads completely. No clicks are necessary except to advance to the next slide.

CLICK to advance to next slide.

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

Suppose that parents request to inspect and review the early intervention records of their baby or toddler. The agency, of course, must respond to this request.

Now suppose that the parents find something in the EI records they believe is—as the slide states—inaccurate or misleading. Or perhaps they believe the information violates their privacy or other rights, or the privacy or other rights of their child.

Do remedies exist for parents to amend the information in the records? Yes. And we'll look at what parents can do across four slides, beginning with this one.

What the Part C Regulations Say

The information on the slide comes nearly verbatim from §303.410(a), which participants can read on **Handout 15**. We provide the text in the box on the next page. Note that §303.410 also has paragraphs (b) and (c), which will be covered in the next slide.

Discussing the Slide

- The text on the slide is fairly self-explanatory and does not need much elaboration as to its meaning. The slide allows you to make the point succinctly, then move on to the next slide, which focuses on the “next steps” following parents’ request that their child’s EI records be amended.

- You may wish to take a moment, however, to make this information more personal or concrete to participants. Ask participants to consider what type of information in a child’s records might strike parents as misleading, inaccurate, or a violation of privacy or other rights.

Participants can also frame the question in terms of *themselves*—in other words, what inaccurate and misleading information might exist in records about themselves or their children? What would they consider a violation of their privacy, were it to be included (and, thus, potentially shared with others) in their own health, insurance, employment, education, or other records? Has anyone had the experience of *seeing* their own records?

§303.410 Amendment of records at a parent’s request.

(a) A parent who believes that information in the early intervention records collected, maintained, or used under this part is inaccurate, misleading, or violates the privacy or other rights of the child or parent may request that the participating agency that maintains the information amend the information.

Slide 10

Amending the Records at Parent Request (*Slide 2 of 4*)

Amending the Records at Parent Request

The agency must decide whether to amend the information as requested

If “no,” the agency must:

- inform the parent of that refusal, and
- advise the parent of the right to a hearing



Opening View:
The slide loads with this view.

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Amending the Records at Parent Request



The question to be answered in a hearing

Is the information in the child's records inaccurate, misleading, or in violation of the privacy of other rights of the child or parent?

Click 1

Click 1: The picture changes, and this new text appears about the "question to be answered in a hearing."

CLICK AGAIN to advance to next slide.

Slide 10: Background and Discussion

Click

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

The situation at hand: Parents have requested that the agency maintaining their child's early intervention records amend those records with respect to information they believe is inaccurate, misleading, or in violation of their (or their child's) privacy or other rights. What happens next?

Decision time! As the slide indicates, the agency must now decide within a reasonable period of time whether or not it is going to amend the information in question as requested by the parents.

Possibility 1 | The agency may well decide to amend the early intervention information as the parents have requested. Once it has done so, it must let the parents know. Done. Issue resolved.

Possibility 2 | Conversely, the agency may decide to refuse the parents' request to amend their child's EI records. In this scenario, as the slide indicates, the agency must inform the parents of its refusal and indicate that they (the parents) have the right to a hearing to challenge the information in their child's records that they believe is misleading, inaccurate, or in violation of privacy or other rights.

If parents request a hearing | Parents don't necessarily have to exercise their right to a hearing. It's their choice. But say that parents *do* request a hearing on this matter. The question to be resolved in the hearing is whether or not the information in the child's records *is* misleading, inaccurate, or in

violation of the privacy or other rights of the child or parents.

The hearing decision | What happens after the hearing will depend on whether the hearing decision is “yes” or “no.” This will be discussed on the next slide!

Trainer’s Note!



Be aware that the above summary lacks regulatory rigor and detail. For your use as a trainer, we provide more detail below. Offer it as appropriate to the purposes of your training and the needs of your participants. The audience may not need this level of detail at the moment, but they will have the Part C regulations to refer to, should they need the regulatory references in future.

What the Part C Regulations Say

The information on the left half of the slide comes nearly verbatim from §303.410(b) and (c), which participants can read on **Handout 15**. We provide the text in the box at the top right. Note that these regulations pick up where the regulations on the previous slide left off.

About the Parents’ Options for a Hearing

Here’s where the regulatory details and references rear their confusing heads. Fasten your seat belt, we’re plunging in!

The regulations just cited refer to the parent’s right to a hearing under §303.411. That’s straightforward enough. The waters get muddier when you look at §303.411, which is presented in the box at the bottom right and on **Handout 15**.

What §303.411 adds in terms of detail is that there are two types of hearings a parent may request, either:

- a **due process hearing** under the procedures in §303.430(d)(1), provided that such hearing procedures meet the requirements of the hearing procedures in §303.413; or

§303.410 Amendment of records at a parent's request.

(a) A parent who believes that information in the early intervention records collected, maintained, or used under this part is inaccurate, misleading, or violates the privacy or other rights of the child or parent may request that the participating agency that maintains the information amend the information.

(b) The participating agency must decide whether to amend the information in accordance with the request within a reasonable period of time of receipt of the request.

(c) If the participating agency refuses to amend the information in accordance with the request, it must inform the parent of the refusal and advise the parent of the right to a hearing under §303.411.



§303.411 Opportunity for a hearing.

The participating agency must, on request, provide parents with the opportunity for a hearing to challenge information in their child’s early intervention records to ensure that it is not inaccurate, misleading, or otherwise in violation of the privacy or other rights of the child or parents. A parent may request a due process hearing under the procedures in §303.430(d)(1) provided that such hearing procedures meet the requirements of the hearing procedures in §303.413 or may request a hearing directly under the State’s procedures in §303.413 (i.e., procedures that are consistent with the FERPA hearing requirements in 34 CFR 99.22).

- a hearing directly under the State’s procedures in §303.413 (that is, the procedures that are consistent with the FERPA hearing requirements in 34 CFR 99.22).

Sigh. Yes, that’s a jumble of cross-references. Which we’ll try to untangle as best we can without an exhaustive discussion of due process that’s beyond the scope of this module.

Context | The 2011 Part C regulations continue to give each State the option of adopting either the due process hearing procedures of Part B¹³ or the ones specified for Part C in IDEA 2004 (under section 639). See 34 CFR §303.430. The jumble of cross-references in §303.411 is necessary to adequately cover the individual aspects of a State’s choice regarding which hearing procedures it may use to resolve disputes regarding requests to amend early intervention records.

Consistency with FERPA | In whatever case, hearings under Part C must be conducted in keeping with the procedures of FERPA, as set forth at 34 CFR 99.22. (More on that in a moment.) The regulatory requirement for this is stated at §303.413, which is included on **Handout 15** and reads simply and unequivocally:



§303.413 Hearing procedures.

A hearing held under §303.411 must be conducted according to the procedures under 34 CFR 99.22.

What does FERPA require with respect to hearings? | Remember that FERPA is written using language and terms appropriate for schools and school-aged children, not early intervention programs and babies or toddlers. Therefore, the Part C regulations adjust specific FERPA terms to match the early intervention population. For example, where FERPA uses the term “education records,” Part C substitutes the operational equivalent of “early intervention records.” Similarly, “school” becomes “EIS providers” and “student” becomes “child.”

All this is to say, when you read 34 CFR 99.22,¹⁴ you have to adjust FERPA terms to the early intervention context. We’ve provided 34 CFR 99.22, verbatim, in the box below. A brief summary of its requirements with respect to the conduct of hearings under Part C might include these points:

- The agency must hold the hearing within a reasonable time after it receives the request for the hearing from the parent.

34 CFR 99.22 What minimum requirements exist for the conduct of a hearing?

The hearing required by § 99.21 must meet, at a minimum, the following requirements:

- (a) The educational agency or institution shall hold the hearing within a reasonable time after it has received the request for the hearing from the parent or eligible student.
- (b) The educational agency or institution shall give the parent or eligible student notice of the date, time, and place, reasonably in advance of the hearing.
- (c) The hearing may be conducted by any individual, including an official of the educational agency or institution, who does not have a direct interest in the outcome of the hearing.

(d) The educational agency or institution shall give the parent or eligible student a full and fair opportunity to present evidence relevant to the issues raised under § 99.21. The parent or eligible student may, at their own expense, be assisted or represented by one or more individuals of his or her own choice, including an attorney.

(e) The educational agency or institution shall make its decision in writing within a reasonable period of time after the hearing.

(f) The decision must be based solely on the evidence presented at the hearing, and must include a summary of the evidence and the reasons for the decision.

- The agency must give the parent notice of the date, time, and place, reasonably in advance of the hearing.
- The hearing may be conducted by any individual, including an official of the agency, who does not have a direct interest in the outcome of the hearing.
- The agency must give the parent a full and fair opportunity to present evidence relevant to the issues raised. The parent may, at his or her own expense, be assisted or represented by one or more individuals of his or her own choice, including an attorney.
- The agency must make its decision in writing within a reasonable period of time after the hearing.
- The decision must be based solely on the evidence presented at the hearing, and must include a summary of the evidence and the reasons for the decision.

References & Footnotes

¹³ Part B's due process hearing procedures are described in section 615 of IDEA 2004 and are adapted for Part C in §303.440 through §303.449 of the Part C's implementing regulations.

¹⁴ 34 CFR 99.22—What minimum requirements exist for the conduct of a hearing? Available online at:
<http://www.gpo.gov/fdsys/pkg/CFR-2011-title34-vol1/xml/CFR-2011-title34-vol1-sec99-22.xml>

Is the information in the child's records inaccurate, misleading, or in violation of the privacy of other rights of the child or parent?



The agency **must**—

- **amend** the information accordingly, &
- **inform** the parent in writing that it has done so



The agency **must** inform parent of the **right to place a statement** in child's early intervention records

Slide loads completely. No clicks are necessary except to advance to the next slide.

CLICK to advance to next slide.

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

The situation at hand | Parents have elected to request a hearing on the matter of their child's records. A hearing is then held to determine if, in fact, the information in the child's EI records is misleading, inaccurate, or in violation of the privacy or other rights of the child or parent.

If "yes" | The slide makes it clear what the agency must do if the hearing decision supports the parents' belief that their child's early intervention records need to be amended. The agency must amend those records accordingly. Then the agency must inform parents in writing that it has amended the records as requested.

If "no" | But suppose the hearing decision is "no," the child's records were not misleading, in accurate, and so on. What then? The agency lets the parents know that they have the right to place a statement in their child's EI records. More on that in a moment.

What the Part C Regulations Say

Where, in the regulations, are these requirements spelled out? At §303.412(a) and (b) (Result of hearing), provided on **Handout 15** and in the box on the next page. As you can see, the "Yes" text on the slide comes nearly verbatim from the regulations, while the "No" text needs a bit more elaboration.

More on the "No" Decision

In this scenario, the hearing decision goes against the parents' belief that their child's EI records are inaccurate, misleading, or in violation of the privacy or other rights of the child or parent. The agency must let parents know that, while the agency *won't* amend the records as requested, parents have the right to place a statement in their child's records. (This is the content presented on the slide.)

What kind of a statement? | According to the regulation, parents may place a statement in the child's records:

- commenting on the information, or
- setting forth any reasons for disagreeing with the decision of the agency.

Continuing the Story at §303.412

There's more to the agency's responsibilities with respect to this child's records, as we'll see on the next slide.

§303.412 Result of hearing.

(a) If, as a result of the hearing, the participating agency decides that the information is inaccurate, misleading or in violation of the privacy or other rights of the child or parent, it must amend the information accordingly and so inform the parent in writing.

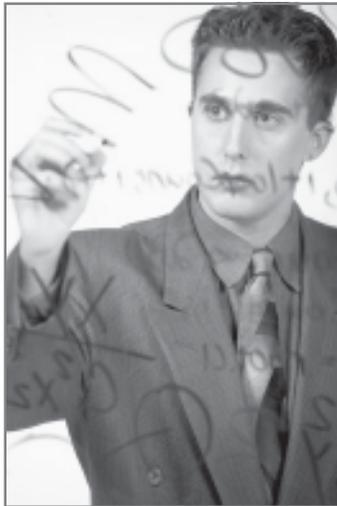
(b) If, as a result of the hearing, the agency decides that the information is not inaccurate, misleading, or in violation of the privacy or other rights of the child or parent, it must inform the parent of the right to place in the early intervention records it maintains on the child a statement commenting on the information or setting forth any reasons for disagreeing with the decision of the agency.

Slide 12

Amending the Records at Parent Request (Slide 4 of 4)

Any explanation placed in the early intervention records of the child **must be—**

Maintained by the agency as part of the child's records as long as the record or contested portion is maintained by the agency



Opening View: Slide loads the header ("Any explanation placed..." and the paragraph "Maintained by the agency.")

Slide continues on next page 

Any explanation placed in the early intervention records of the child **must be—**

Maintained by the agency
as part of the child’s records
as long as the record or
contested portion is
maintained by the agency

If records are disclosed
If the records or the contested
portion are disclosed by the
agency to any party—
—the explanation **must also**
be disclosed to the party



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changes, and this
new text appears
about the “question
to be answered in a
hearing.”

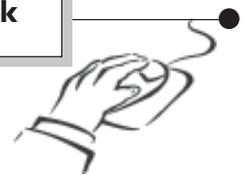
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Slide 12: Background and Discussion

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Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)



Last slide on the subject of amending a child’s records at the parents’ request. This slide brings forward an important aspect of record-keeping, confidentiality, and privacy we haven’t mentioned yet. Now’s the time.

But first... picking up where we left off in the last slide...

Scenario | Let us suppose that the parents decide to include a statement in their child’s EI records, setting forth the reasons they disagree with the hearing decision. As required, the agency places this statement in the child’s records.

How long must the agency maintain that statement in the child’s records? | As the slide indicates, and as the regulations state, the parents’ explanation that’s placed in the child’s records must be maintained in those records by the agency for as long as the record or contested portion is maintained by the agency.

Under what circumstances may the agency omit the parents’ statement when the child’s records are disclosed? | The agency may not omit the parents’ statement when the child’s records (or the contested portion of those records) are disclosed by the agency to any party. The parents’ explanation must also be disclosed.

What the Part C Regulations Say

Where, in the regulations, are these requirements spelled out? At §303.412(c) (Result of hearing), provided on **Handout 15** and in the box below. The last slide looked at (a) and (b) of §303.412, and we continue here with (c).

Discussing the Slide

Not one without the other | When a portion or all of a child's early intervention records has been unsuccessfully contested, the explanation that parents may include in their child's records becomes part of that child's records. It must be maintained as part of those records for as long as the agency maintains the child's records. If the contested part of the record is shared with any party, then the parents' statement must also be shared. Not one without the other.

For how long do the confidentiality procedures in early intervention apply? | Children enter early intervention as infants or toddlers, and most age-out when they turn three, moving on to other programs or settings. Does "time" then run out for protecting the personally identifiable information in their records? The answer can be found at §303.401(c)(2) of the Part C regulations, which appears on **Handout 15** and in the box on the bottom right.

As this provision states, the answer depends on the obligations and policies of the participating agency. Federal and State laws guide how long the agency is *required* to maintain the PII of the child and family (its obligation). State laws and policies may also be a factor, for these may specify a longer timeframe for maintaining records than is required by law.

What happens to the early intervention record when the information is no longer needed? | The participating agency must inform parents when the early intervention records are no longer needed to provide services to the child under Part C of the Act and other laws and provisions.¹⁵ Further, the agency must destroy the information at the request of the parents.



§303.412 Result of hearing.

(a) If, as a result of the hearing, the participating agency decides that the information is inaccurate, misleading or in violation...

(b) If, as a result of the hearing, the agency decides that the information is not inaccurate, misleading, or in violation ...

(c) Any explanation placed in the early intervention records of the child under this section must—

(1) Be maintained by the agency as part of the early intervention records of the child as long as the record or contested portion is maintained by the agency; and

(2) If the early intervention records of the child or the contested portion are disclosed by the agency to any party, the explanation must also be disclosed to the party.

How long do the confidentiality provisions in early intervention apply?

(c) Applicability and timeframe of procedures. The confidentiality procedures described in paragraph (b) of this section apply to the personally identifiable information of a child and the child's family that—

(1) Is contained in early intervention records collected, used, or maintained under this part by the lead agency or an EIS provider; and

(2) Applies from the point in time when the child is referred for early intervention services under this part until the later of when the participating agency is no longer required to maintain or no longer maintains that information under applicable Federal and State laws. [§303.401(c)(2)]

However, a permanent record regarding the child may be maintained without time limitation. This permanent record includes:

- the child's name,
- date of birth,
- parent contact information (including address and phone number),
- names of service coordinator(s) and EIS provider(s), and
- exit data (including year and age upon exit, and any programs entered into upon exiting).

The regulations in Part C stipulating these requirements is found at §303.417, which is provided on **Handout 15** and in the box below.

Footnote

¹⁵ Other laws and provisions include the GEPA provisions in 20 U.S.C. 1232f, and EDGAR, 34 CFR parts 76 and 80. These are listed in the Part C regulations at §303.417.



§303.416 Destruction of information.

(a) The participating agency must inform parents when personally identifiable information collected, maintained, or used under this part is no longer needed to provide services to the child under Part C of the Act, the GEPA provisions in 20 U.S.C. 1232f, and EDGAR, 34 CFR parts 76 and 80.

(b) Subject to paragraph (a) of this section, the information must be destroyed at the request of the parents. However, a permanent record of a child's name, date of birth, parent contact information (including address and phone number), names of service coordinator(s) and EIS provider(s), and exit data (including year and age upon exit, and any programs entered into upon exiting) may be maintained without time limitation.

Final Points

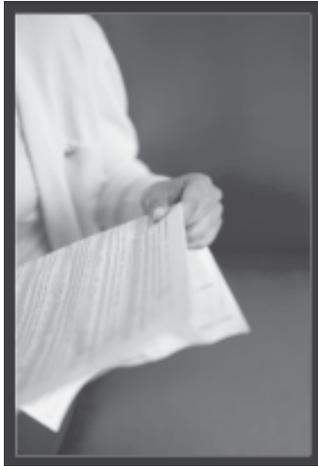


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CLICK to advance to next slide.

This is a quick slide, alerting everyone that we're in the home stretch of this training module and the next slides are "final points" to be learned about the parents' right to inspect and review their child's early intervention records.

Record of Access



Each agency **must keep a record** of parties obtaining access to early intervention records:—

name, date of access, & purpose for which the party is authorized to use the early intervention records

Exceptions:

Parents, authorized representatives and employees of the agency

Slide loads completely. No clicks are necessary except to advance to the next slide.

CLICK to advance to next slide.

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

Also part of maintaining the confidentiality of the personally identifiable information in children's early intervention records is the focus of this slide: maintaining a record of who has obtained access to those records. Having such a list provides another layer of protection for families and children involved in Part C, as well as a level of transparency and accountability for participating agencies.

Specifics of the Record to be Maintained

What's recorded? | As the slide indicates, the information that must be recorded when someone obtains access to a child's EI record is:

- the individual's name;
- the date when he or she accessed the records; and
- the purpose for which the person is authorized to use the EI records.

Exceptions | There are notable exceptions regarding who must be noted in the Record of Access. Parents are excepted. And so are authorized representatives and employees of the participating agency.

What the Part C Regulations Say

Where, in the regulations, are the requirements for keeping a record of access spelled out? At §303.406. Participants can find this provision on **Handout 15**, which reads as follows:

§303.406 Record of access.

Each participating agency must keep a record of parties obtaining access to early intervention records collected, maintained, or used under Part C of the Act (except access by parents and authorized representatives and employees of the participating agency), including the name of the party, the date access was given, and the purpose for which the party is authorized to use the early intervention records.

Authorized versus Non-Authorized

Who is automatically “authorized” as a representative or employee of the participating agency to access a child’s early intervention

records? The answer to this will be spelled out in the State’s confidentiality policies and procedures. As was mentioned under Slide 4:

- Participating agencies must comply with Part C’s confidentiality provisions and the State’s policies; and
- All people collecting or using PII in Part C must receive training or instruction regarding the State’s confidentiality policies.

Generally speaking, however, officials and employees of participating agencies collecting or using the information *for the purposes of the early intervention program* would be considered “authorized.” Some will have monitoring and oversight duties to perform. Others are involved in the delivery of early intervention services.

When is Parent Consent Needed?

We’ll get to that very important question on the next slide.

Slide 15

Parental Consent for Disclosure or Use

Parental Consent for Disclosure or Use

When is **parental consent** needed to disclose or use **personally identifiable information**?



Opening View:
Slide loads with only the question and a picture of a parent.

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Slide 15 began on the previous page

Parental Consent for Disclosure or Use

When is **parental consent** needed to disclose or use **personally identifiable information**?

Prior parental consent is **required** before PII may be:

- disclosed to anyone other than those authorized
- used for any purpose other than meeting a requirement of Part C

Note that there are **exceptions**

Click 1

Click 1:
The picture lifts away, and the answer to the question appears, including that there are “exceptions.”

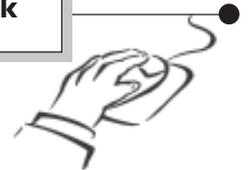
CLICK AGAIN to advance to next slide.

Slide 15: Background and Discussion

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

Click



Given the importance of maintaining confidentiality, it's not surprising that parental consent would most likely be needed before a participating agency in Part C may disclose PII about the child or the family to a third party that is not authorized by the agency as a representative, official, or employee. We say “most likely,” because there are exceptions.

The governing regulations regarding parental consent can be found at §303.414. These are provided on **Handout 15**, shown in the big box on the next page, and summarized below.

Summary Points

We're not going to delve deeply into the specifics of §303.414. There are numerous cross-references to other provisions in the Part C regulations and to FERPA. Most participants will not need the level of detail it would take to go through and explain each of the cross-references, although we *do* provide, for your convenience as a trainer, a list of what each is alluding to. The salient points are summarized in what follows.

Bottom line | Parental consent is required before a child's or family's PII may be disclosed to an unauthorized individual or agency or used for a purpose other than meeting a Part C requirement.

Exceptions | As the slide notes, there are exceptions to the need for parental consent. These exceptions are identified in IDEA or in the exceptions in FERPA.

- **Example** | A Part C exception to the need for parental consent: When a toddler in Part C is approaching his or her 3rd birthday (the point

in time when most toddlers "age out" of early intervention services), and that child may be eligible to receive special education and related services under Part B of IDEA, the lead agency is required to notify the SEA and the child's LEA that the child may soon be eligible under Part B. What PII is the lead agency required to disclose? The child's name, his or her date of birth, and parents' contact information.¹⁶

Note: Some States have chosen to adopt an "opt-out" policy that gives parents the opportunity to block the



§303.414 Consent prior to disclosure or use.

(a) Except as provided in paragraph (b) of this section, prior parental consent must be obtained before personally identifiable information is—

(1) Disclosed to anyone other than authorized representatives, officials, or employees of participating agencies collecting, maintaining, or using the information under this part, subject to paragraph (b) of this section; or

(2) Used for any purpose other than meeting a requirement of this part.

(b) A lead agency or other participating agency may not disclose personally identifiable information, as defined in §303.29, to any party except participating agencies (including the lead agency and EIS providers) that are part of the State's Part C system without parental consent unless authorized to do so under—

(1) Sections 303.401(d), 303.209(b)(1)(i) and (b)(1)(ii), and 303.211(b)(6)(ii)(A); or

(2) One of the exceptions enumerated in 34 CFR 99.31 (where applicable to Part C), which are expressly adopted to apply to Part C through this reference. In applying the exceptions in 34 CFR 99.31 to this part, participating agencies must also comply with the pertinent conditions in 34 CFR 99.32, 99.33, 99.34, 99.35, 99.36, 99.38, and 99.39; in applying these provisions in 34 CFR part 99 to Part C, the reference to—

(i) 34 CFR 99.30 means §303.414(a);

(ii) "Education records" means early intervention records under §303.403(b);

(iii) "Educational" means early intervention under this part;

(iv) "Educational agency or institution" means the participating agency under §303.404(c);

(v) "School officials and officials of another school or school system" means qualified personnel or service coordinators under this part;

(vi) "State and local educational authorities" means the lead agency under §303.22; and

(vii) "Student" means child under this part.

(c) The lead agency must provide policies and procedures to be used when a parent refuses to provide consent under this section (such as a meeting to explain to parents how their failure to consent affects the ability of their child to receive services under this part), provided that those procedures do not override a parent's right to refuse consent under §303.420.

otherwise required disclosure. In these States, if the parent objects to the disclosure of PII, then the agency or EIS provider is not permitted to make the disclosure of information about the child to the SEA or the child's LEA.¹⁷

- **Example | A FERPA exception to the need for parental consent:** The cross-reference to FERPA is tied to provisions at 34 CFR 99.31, which asks the question: Under what conditions is prior consent not required to disclose information?¹⁸ In answer, examples of permissible occasions when PII may be disclosed without parental consent under FERPA include:

- disclosure of PII to an individual or agency who has been determined to have “legitimate educational interests” in the information; and
- disclosure of PII in connection with financial aid for which the student has applied or is receiving.

Note: FERPA's answer must be adjusted so that its terminology relates to children served under Part C and their early intervention records (not to school-aged children and their education records). Thus, we're talking about the disclosure of PII about a child in early intervention to an individual or agency that has been determined to have “legitimate early intervention interests” in the information. This may be an early intervention service provider, an employee of the lead agency, or a contractor, or other party to whom a participating agency has outsourced institutional services or functions.

Brief examples don't tell the full story | Please note that these are brief examples of when or to whom a child's PII may be disclosed without parental consent. They are not legally sufficient examples, in the sense that much more detail is involved in spelling out the permissible occasions and accompanying conditions under which a disclosure of PII may be made.

What if the parents refuse consent? | It's certainly possible that parents may refuse to give their consent for the disclosure of personally

identifiable information about their child or themselves. That's why the Part C regulations require lead agencies to have policies and procedures to be used in the event of parents refusing to give consent. This might include meeting with parents to explain how their failure to consent affects the ability of their child to receive early intervention services. In any event, the procedures and policies that the lead agency uses may not override a parent's right to refuse consent.¹⁹



Decoding the Cross-References

Here, at last, we come to the handy list of the cross-references in §303.414.

Section 303.401(d) | Confidentiality and opportunity to examine records: Disclosure of information. *See Handout 15.*

Section 303.209(b)(1)(i) and (b)(1)(ii) | Transition to preschool and other programs: Notification to the SEA and appropriate LEA.

Section 303.211(b)(6)(ii)(A) | State option to make services under this part available to children ages three and older—Requirements. *[This is the extended Part C option.]*

34 CFR 99.30 | FERPA—Under what conditions is prior consent required to disclose information?

99.31 | FERPA—Under what conditions is prior consent not required to disclose information?

99.32 | FERPA—What recordkeeping requirements exist concerning requests and disclosures?

99.33 | FERPA—What limitations apply to the redisclosure of information?

99.34 | FERPA—What conditions apply to disclosure of information to other educational agencies or institutions?

99.35 | FERPA—What conditions apply to disclosure of information for Federal or State program purposes?

99.36 | FERPA—What conditions apply to disclosure of information in health and safety emergencies?

99.38 | FERPA—What conditions apply to disclosure of information as permitted by State statute adopted after November 19, 1974, concerning the juvenile justice system?

99.39 | FERPA—What definitions apply to the nonconsensual disclosure of records by postsecondary educational institutions in connection with disciplinary proceedings concerning crimes of violence or nonforcible sex offenses?

References

¹⁶ §303.401(d)—Confidentiality and opportunity to examine records: Disclosure of information. See also §303.209(b)(i) and (b)(1)(ii)—Transition to preschool and other programs: Notification to the SEA and appropriate LEA.

¹⁷ §303.401(e)—Confidentiality and opportunity to examine records: Option to inform a parent about intended disclosure.

¹⁸ 34 CFR 99.31—Under what conditions is prior consent not required to disclose information? The FERPA regulations are available online at: <http://www2.ed.gov/policy/gen/guid/fpco/pdf/ferparegs.pdf>

¹⁹ §303.414(c)—Consent prior to disclosure or use. See also §303.420—Parental consent and ability to decline services.

Records on More Than One Child

If any early intervention record includes information on more than one child —



Parents of those children have the right to:

- inspect & review *only* the info relating to their child, *or*
- be informed of that specific information

Slide loads completely. No clicks are necessary except to advance to the next slide.

CLICK to advance to next slide.

Pertinent Handouts:

- Handout 15, Confidentiality Provisions (verbatim regulations)

Last content slide, which means you're almost done with this training module. Finish this one "final point"—happily, it's a quick point to make.

Situation | Sometimes early intervention records contain information on more than one child. If parents have the right to inspect and review their child's records, how does the participating agency

§303.407 Records on more than one child.

If any early intervention record includes information on more than one child, the parents of those children have the right to inspect and review only the information relating to their child or to be informed of that specific information.

protect the confidentiality of the information about other children that may be in those records?

Answer | Parents may inspect and review *only* the information that relates to their child. This means that the agency must:

- somehow separate out or redact the information about the other children, so the inspecting and reviewing parents don't see their PII; or
- tell or otherwise inform the parents about the specific information they wish to inspect and review in their child's records.

That's quite clear, isn't it? And it's definitely in keeping with everything that's been said in this module about confidentiality and the importance of protecting each child's (and family's) personally identifiable information.



Round-Up Time!

Slide loads completely. No clicks are necessary except to END the slideshow.

CLICK to END the sldieshow.

Pertinent Handout:

- Activity Sheet 15 | Reflecting on Part C's Procedural Safeguards

Hurrah! You've gotten to the last slide and can almost count the session "done." Depending on how much time you have available, you can use this slide to:

- hold a quick review and recap of your own devising;
- open the floor up for a question and answer period;
- have participants complete a closing activity of your choice and discuss in the large group afterwards; or
- have participants complete **Activity Sheet 15** individually and discuss their answers in the large group afterwards.

Optional Activity

Total Time Activity Takes: 15 minutes.

Group Size: Individual, then large group

Materials: Activity Sheet 15, Review Time | Early Intervention Records

Instructions

Refer participants to **Activity Sheet 15**. Indicate that they are to complete the activity sheet individually. Allow the audience 10 minutes to complete the activity sheet, then call them back to large-group focus and discussion of their answers and their learning.