

Module 10

Introduction to Procedural Safeguards



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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 *Introduction to Procedural Safeguards* and is the 10th 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



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

Procedural Safeguards

The 2004 Amendments to the Individuals with Disabilities Education Act (IDEA) include many protections and safeguards—as did previous amendments to the Act. In the Part C regulations that were promulgated on September 28, 2011 (and effective beginning with the grant year on July 1, 2012), an

entire section is devoted to Procedural Safeguards. These safeguards are designed to protect the rights of parents and their infant or toddler with a disability, as well as give families and early intervention lead agencies a mechanism for resolving disputes.

What are procedural safeguards? | Ask five people and you might easily get five different answers, including at least one response of, "Huh?"

The term *procedural safeguards* sounds rather legalistic and perhaps even a little scary. When it comes to helping our youngest children with disabilities address their developmental needs, what or who needs to be safeguarded? The children? Parents? Early intervention service (EIS) providers or the lead agency in



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.

charge of making early intervention services available to infants and toddlers with disabilities and their families in the State?

Procedural safeguards as umbrella | For our purposes, procedural safeguards are a set of requirements that provide an umbrella of protection to safeguard the rights of infants and toddlers who are referred for early intervention services, as well as the rights of their parents. Each State's lead agency (which is responsible for making early intervention services available for young children with disabilities under the age of three) also is responsible for ensuring the implementation of IDEA's procedural safeguards. The lead agency also has certain specific rights related to these safeguards and most certainly a host of responsibilities.

Lead agency responsibilities for procedural safeguards | Each lead agency is responsible for establishing procedural safeguards that meet the requirements of 34 CFR 303.400, Subpart E.⁵ The procedural safeguards include provisions related to:

- confidentiality of the child and family's early intervention records;
- the right of parents to review such records;
- data collection and consent related to the disclosure of personally identifiable information;
- prior written notice, which ensures that parents receive important information about the lead agency or EIS provider's proposed actions or refusals; and
- parental consent for actions affecting infants and toddlers and their families.

The procedural safeguards also:

- ensure that the child's rights are protected if a surrogate parent must be assigned;
- establish dispute resolution procedures to ensure speedy resolution of any disputes that arise under Part C of the IDEA; and
- contain requirements regarding the State's system of payments.



In addition to establishing these procedures, the lead agency is responsible for ensuring the effective implementation of these safeguards throughout its Statewide system that is involved in the provision of early intervention services under Part C of the IDEA.

In this overview, we will introduce some prominent procedural safeguards and see how these correspond to the rights of infants and toddlers with disabilities and their parents, and to the rights and responsibilities of early intervention lead agencies throughout the United States.

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) are being developed, finalized, and published:

- *Introduction to Procedural Safeguards* (this module), 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;

- *Access to and Examination of Records* (Module 12), 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 the protections known as IDEA Part C’s procedural safeguards. The potential audience 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, including the role that procedural safeguards play in protecting the rights and privacy of families and children receiving early intervention services;
- 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.

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-module10/>

Files You’ll Need for This Module

Slideshow. We are pleased to provide a slideshow (produced in PowerPoint®) which trainers can use to introduce Part C’s procedural safeguards. 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.

- **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.

- **Handouts for Participants.** The following handouts are available:

Handout 7 | Parent Notification and Consent

Handout 14 | Part C’s Confidentiality Provisions: Summary of Key Points

Handout 15 | Part C’s Confidentiality Provisions: Verbatim Regulations

Handout 16 | System of Payments and Use of Insurance in Part C: Summary of Key Points

Handout 17 | Procedural Safeguard: Appointing a Surrogate Parent for a Child

Handout 18 | Dispute Resolution Options: Summary of Key Points

Handout 19 (*optional*) | Dispute Resolution Options: Verbatim Regulations

- **Activity Sheet 14 (*optional*).** This activity sheet is provided as a closing activity to the training session and asks participants to reflect for a moment on Part C’s procedural Safeguards.

- **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.

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 CFR stands for the *Code of Federal Regulations*. 34 CFR means Title 34 of the *Code of Federal Regulations*. 34 CFR 303.400, Subpart E, is where you'll find Part C's procedural safeguards requirements.



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)

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>



Introduction to Procedural Safeguards

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: the procedural safeguards included in the Part C regulations.

You may wish to ask your audience, “What are procedural safeguards?” and see what they say. Can they name any specific safeguards they know? You also might take a moment to look at how the Merriam-Webster dictionary defines these two words:

Procedural—of or relating to the procedure used by courts or other bodies administering substantive law⁶

Safeguard—something that provides protection against possible loss, damage, etc.⁷

Where might issues or conflicts arise between early intervention service or EIS providers and parents with respect to an infant or toddler with a disability and the early intervention services that the child or family receives? You can discuss this briefly with the audience, taking a few ideas to illustrate where protections under the law might be important.

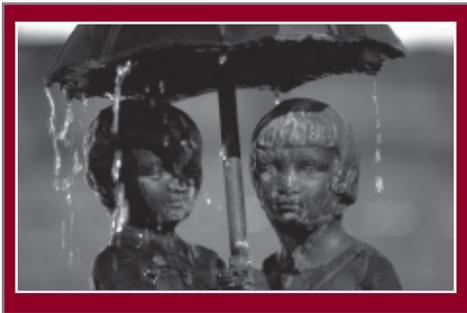
References & Footnotes

⁶ Merriam-Webster Online. (2014). *Procedural*. Retrieved December 16, 2014, from <http://www.merriam-webster.com/dictionary/procedural>

⁷ Merriam-Webster Online. (2014). *Safeguard*. Retrieved December 16, 2014, from <http://www.merriam-webster.com/dictionary/safeguard>

This module provides an overview of Part C's procedural safeguards, including...

- Parent consent and written notice to parents
- Confidentiality
- Appointing a surrogate parent
- Overview of options for resolving disputes



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

CLICK to advance to next slide.

Slide 2 is an advance organizer for the audience, to alert them to the areas covered in this training module and, hopefully, what they'll learn.

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 (procedural safeguards in Part C), 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 procedural safeguards, 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.

Procedural Safeguards in a Nutshell



Procedural safeguards:

- are designed to **protect the rights** of infants and toddlers with disabilities and their families
- offer **options for resolving disagreements** that arise under Part C of IDEA

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CLICK to advance to next slide.

This slide captures the essence of procedural safeguards. The many safeguards included in IDEA all have the same basic purposes, which are shown on the slide. Safeguards protect the rights of children and families in early intervention, even as they offer lead agencies, early intervention providers, and families a variety of options for resolving disagreements that may arise.

Quite similar procedural safeguards exist in Part B of IDEA as well. There, they protect the rights of pre-school, and school-aged, children with disabilities and their families, as well as offer dispute resolution options to families and schools.

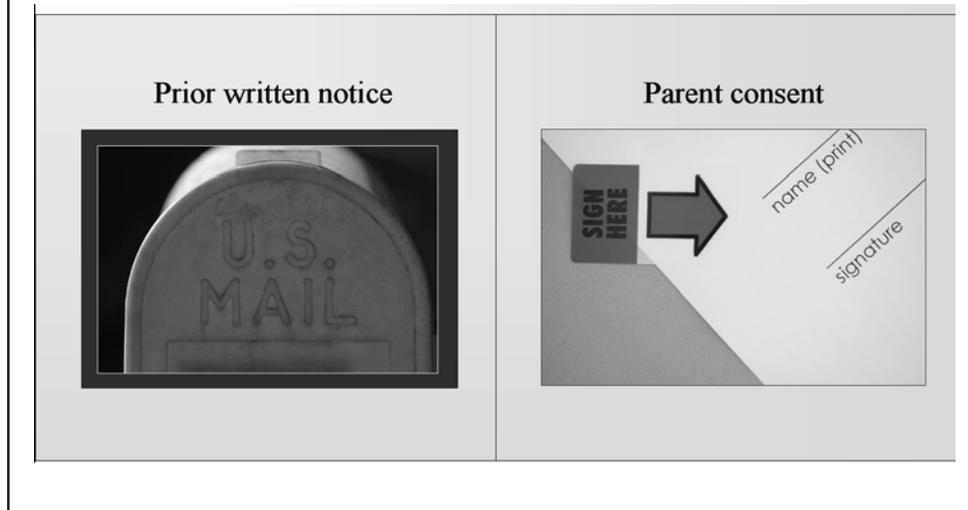
Discussing the Slide

Indicate to participants that the succinct statements on the slide speak to the purposes of Part C's procedural safeguards. You'll be adding more detail about the two main purposes summarized on the slide. For example:

- **Rights** | Parents and their infants/toddlers in Part C have specific rights. We'll be looking at those rights, including the right to give or decline consent for services or actions that the lead agency or EI provider might propose.
- **Options for resolving disputes** | Part C offers families and the EI system multiple ways of resolving disputes, including mediation and due process. We'll briefly look at what those options are.

Okay, time to dive in! "Rights" first, then the "options for resolving disputes."

Two Parental Rights as Safeguards



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

CLICK to advance to next slide.

Pertinent Handout:

- Handout 7, Parent Notification and Parent Consent

Slide 4 introduces two very important aspects in early intervention: the need to fully inform parents via prior written notice and the need for parental consent as critical points in time. It's intended as a brief slide to set up the deeper discussion of both subjects as we move through the next two slides.

Context | Parents as a Child's Most Vital Resource

When parents first enter the early intervention system, it's typically because they are (or someone else is) concerned about their infant or toddler's development, or in some limited cases, the infant or toddler has already been diagnosed with a condition that raises questions about the child's developmental trajectory. Parents may have been referred to the early intervention system by their child's doctor, a family member, a daycare provider, or the neonatal unit at the hospital where their child

was born. Parents themselves may seek out the early intervention system, worried that their baby or toddler isn't hitting predictable milestones of development, for example.

Regardless of how parents and child come to the early intervention system, it's a whole new experience to them. They are likely to be unfamiliar with the processes and procedures used in early intervention, the jargon or specialized vocabulary they may hear, and what awaits their child and family in this program. There's a lot to learn and a lot to decide immediately—for example:

- what's involved in having their child evaluated to see if their child does, indeed, have a developmental delay or disability;
- whether or not they, as parents, want to participate in the assessment of the family's resources and priorities; and

- what early intervention services are appropriate for their infant or toddler and/or acceptable to them as parents, should their child be found eligible for Part C.

All this takes place in the context of parents’ vital role in caring for their baby or toddler. From its earliest roots, the early intervention system has recognized that parents are the most important and influential resource in the lives of their babies and toddlers with disabilities. They are also the primary decision makers for their child.⁸

To be able to make sound decisions about their child’s involvement in early intervention—and their own involvement—parents need to be fully informed about what will take place and where, what’s being proposed or rejected, and much more. To that end, early intervention service providers are required to provide **notice** to parents at specific points in time and to obtain their **consent** before certain activities may take place.

What’s Prior Written Notice?

Prior written notice refers to the notification that must be provided to parents a reasonable time before the lead agency or an EIS provider proposes (or refuses) to “initiate or change the identification, evaluation, or placement of their infant or toddler, or the provision of early intervention services to the infant or toddler with a disability” and his or her family.⁹ Participants can see these exact words on **Handout 7**.

The notice must be in sufficient detail to inform parents about—

- the action that is being proposed or refused;
- the reasons for taking the action; and
- all procedural safeguards that are available to parents including the three major dispute resolution options (e.g., mediation, filing a State complaint or a due process complaint, and the relevant timelines for these options).¹⁰



Examples | Several examples will serve to illustrate when prior written notice must be provided to parents.

- The lead agency or EIS provider wants to screen the child to see if there’s reason to suspect if the child has a disability or developmental delay. (Proposed action: Screening)
- The lead agency or EIS provider wants to evaluate the child to see if he or she is eligible for Part C services because of a disability or developmental delay. (Proposed action: Evaluation)
- The lead agency or EIS provider wants to develop an individualized family service plan or IFSP for the child. (Proposed action: Provision of early intervention services and/or Placement)

In each of these instances, the parents would need to be provided with prior written notice by the lead agency or EIS provider. These are not the only times that prior written notice is required, but they are among the first instances that parents new to early intervention would encounter.

More will be said about prior written notice on the next slide. Introducing it here, in tandem with parental consent, highlights the close connection the two safeguards have to each other.

Parental Consent

Consent within IDEA has a very specific meaning that is closely tied to prior written notice. Consent, in IDEA, means *informed written consent*. Prior written notice comprehensively describes a proposed or refused action and is intended to inform parents fully about a specific issue. Only by building that foundation of understanding can *informed* consent be given.

Consider the definition of *consent* in the Part C regulations (provided at the bottom of page 2 on **Handout 7**, as well as in the box on the next page). While participants will most likely have an intuitive and experience-based grasp of what

§303.7 Consent.

Consent means that—

(a) The parent has been fully informed of all information relevant to the activity for which consent is sought, in the parent’s native language, as defined in §303.25;

(b) The parent understands and agrees in writing to the carrying out of the activity for which the parent’s consent is sought, and the consent form describes that activity and lists the early intervention records (if any) that will be released and to whom they will be released; and

(c)(1) The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time.

(2) If a parent revokes consent, that revocation is not retroactive (i.e., it does not apply to an action that occurred before the consent was revoked).



“consent” means, this definition includes several points worth bringing to their attention:

- Consent is voluntary on the part of the parent. It’s not a one-shot-and-done action. Parents may withdraw (revoke) their consent at any time.
- Requesting parents’ consent for a given action must occur in the parents’ native language (more on native language on the next slide).
- When required, parental consent must be given in writing. It’s insufficient for parents to provide only verbal agreement.

More will be said about parental consent on Slide 6, including the specific points in time when parental consent is required for an action or activity to take place. For now, make it clear to your participants that the right to give or refuse consent for pivotal activities is an important procedural safeguard for parents. It recognizes their authority and responsibility in making decisions about their child’s involvement in early intervention, and the family’s.

References

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- ⁸ Hurth, J., & Goff, P. (2002, June). *Assuring the family’s role on the early intervention team: Explaining rights and safeguards*. Chapel Hill, NC: National Early Childhood Technical Assistance Center. Online at: <http://www.nectac.org/~pdfs/pubs/assuring.pdf>
 - ⁹ §303.421(a)—Prior written notice and procedural safeguards notice: General.
 - ¹⁰ §303.421(b)—Prior written notice and procedural safeguards notice: Content of notice.

Prior Written Notice



Written notice must be:

- written in language understandable to the general public
- provided in native language of parent or other mode of communication used by parent*

* Unless it is clearly not feasible to do so

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

CLICK to advance to next slide.

Pertinent Handout:

- Handout 7, Parent Notification and Parent Consent

This slide continues the discussion of the prior written notice that lead agencies and EI providers are required to provide to parents at specific points in time—namely, a reasonable time before the lead agency or an EIS provider proposes (or refuses) to “initiate or change the identification, evaluation, or placement of their infant or toddler, or the provision of early intervention services to the infant or toddler with a disability” and his or her family.¹¹

Can Parents Understand the Prior Written Notice They Receive?

One point now is the importance of ensuring that the prior written notice is understandable to the parent. Otherwise, it wouldn't be very informative!

As the slide indicates, there are two elements involved in making the notice understandable:

1. The notice must be written in language that the general public can understand.

2. The notice must be provided to the parent in his or her native language or other mode of communication, unless it's clearly not feasible to do so.

Let's look at each of these elements. We provide more information than you may need to pass along to participants, so pick and choose among the details to match the needs of your audience and the time available for your training session.

Language that the General Public Would Understand

Ask participants what things in a written document can impede a typical person's understanding of that document. You might hear answers such as:

- use of jargon or acronyms
- unfamiliar technical terms
- legal words and concepts

- medical terminology
- dense, complicated, long sentences

Average reading level of the general public | Here are some eye-opening statistics about how well the general public reads.

- According to research, the average adult reads below the 9th grade reading level; to reach the vast majority of adults, the reading level should be at the 5th grade level.¹²
- Newspapers are written at the 11th grade level.
- Blockbuster novels (such as those by John Grisham) tend to be written at the 7th grade level, romance novels at the 5th grade level.
- Disturbingly, 14% (30 million) of adults in the U.S. are functioning at Below Basic, defined simply as “not having adequate reading skills for daily life” (e.g., cannot understand the instructions on a medicine container or read a story to their children).¹³

What’s recommended, then? | So, what reading level should lead agencies shoot for? Health and safety information should be written at the 5th-grade level.¹⁴ And, in keeping with the government’s Plain Language Initiative, materials need to be written in plain, easy-to-understand language.¹⁵

How do you determine a document’s reading level? | There are several formulas you can use to test the reading level of a given text. Perhaps the most well-known is the Flesch-Kincaid Grade Level, but it’s helpful to test your text in several different formulas and see what results you get. Here’s a quick link to free readability formulas, a website offering free information and tools to understand readability formulas, at:

<http://www.readabilityformulas.com/>

The Reality of Limited English Proficiency

Now consider the impact of limited English proficiency on a person’s ability to read—and understand—information that’s written in English. There are over 25.2 million people in the U.S. over the age of 5 who do not speak English well or at all.¹⁶ Point this out to participants, and perhaps throw in a few fascinating statistics on the languages used instead.

- The U.S. Census Bureau codes 382 detailed languages spoken in the U.S., and clusters them into four main language groups: Spanish, other Indo-European languages, Asian and Pacific Island languages, and “All Other Languages.” The information in the box below is a real eye-opener about the sheer diversity of languages spoken,

The U.S. Census Bureau’s Four Major Language Groups¹⁷

Spanish includes Spanish, Spanish Creole, and Ladino.

Other Indo-European languages include most languages of Europe and the Indic languages of India. These include the Germanic languages, such as German, Yiddish, and Dutch; the Scandinavian languages, such as Swedish and Norwegian; the Romance languages, such as French, Italian, and Portuguese; the Slavic languages, such as Russian, Polish, and Serbo-Croatian; the Indic languages, such as Hindi, Gujarati, Punjabi, and Urdu; Celtic languages; Greek; Baltic languages; and Iranian languages.

Asian and Pacific Island languages include Chinese; Korean; Japanese; Vietnamese; Hmong; Khmer; Lao; Thai; Tagalog or Pilipino; the Dravidian languages of India, such as Telugu, Tamil, and Malayalam; and other languages of Asia and the Pacific, including the Philippine, Polynesian, and Micronesian languages.

All Other languages include Uralic languages, such as Hungarian; the Semitic languages, such as Arabic and Hebrew; languages of Africa; native North American languages, including the American Indian and Alaska native languages; and indigenous languages of Central and South America.

including the 169 distinct native North American languages spoken in the U.S.

- The top 10 non-English languages spoken in the U.S. are: Spanish, Chinese, French, Tagalog, Vietnamese, German, Korean, Russian, Italian, and Portuguese.¹⁸
- The U.S. Census Bureau regularly collects information about the languages used by people living in the United States and is quick to point out that speaking a language other than English does not necessarily mean that a person can't speak English well. Many millions do, in fact—some *very* well.
- But consider the number of people who indicated to the Census Bureau that they spoke English “not well” and “not at all.” Of the approximately 60.6 million people who speak a non-English language at home, some 22.4% either don't speak English well or they don't speak English at all. That's approximately 13.6 million people.

Concluding the obvious | Given the average reading level of an adult in the U.S. and the number of people who don't speak English well or at all, there can be no mistaking the enormous need for lead agencies and EI providers to make all communications with the families they serve as easy to understand as possible.

Prior Written Notice in the Parents' Native Language or Other Mode of Communication

The Part C regulations are exceedingly clear that prior written notice must be provided to parents in their native language (or other mode of communication), unless it is clearly not feasible to do so.¹⁹ You'll find the applicable regulations in the box below and on **Handout 7**.

Definition of “native language” | The Part C regulations provide a definition of “native language” at §303.25, which reads as follows:

§300.25 Native language.

(a) *Native language*, when used with respect to an individual who is limited English proficient or LEP (as that term is defined in section 602(18) of the Act), means—

(1) The language normally used by that individual, or, in the case of a child, the language normally used by the parents of the child, except as provided in paragraph (a)(2) of this section; and

(2) For evaluations and assessments conducted pursuant to § 303.321(a)(5)

Continued on next page 

Providing Prior Written Notice in Parents' Native Language or Other Mode of Communication | §303.421(c)

(c) *Native language*. (1) The notice must be—

(i) Written in language understandable to the general public; and

(ii) Provided in the native language, as defined in §303.25, of the parent or other mode of communication used by the parent, unless it is clearly not feasible to do so.

(2) If the native language or other mode of communication of the parent is not a written

language, the public agency or designated EIS provider must take steps to ensure that—

(i) The notice is translated orally or by other means to the parent in the parent's native language or other mode of communication;

(ii) The parent understands the notice; and

(iii) There is written evidence that the requirements of this paragraph have been met.

and (a)(6), the language normally used by the child, if determined developmentally appropriate for the child by qualified personnel conducting the evaluation or assessment.

(b) *Native language*, when used with respect to an individual who is deaf or hard of hearing, blind or visually impaired, or for an individual with no written language, means the mode of communication that is normally used by the individual (such as sign language, braille, or oral communication).

Beyond limited English proficiency | As you can see, the definition of *native language* doesn't merely apply to individuals who are limited English proficient. The definition also includes what *native language* means for:

- an individual with deafness;
- an individual with blindness;
- an individual for whom there is no written language; and
- the infant or toddler who has come to the early intervention program for screening or evaluation, or who is receiving early intervention services to address a developmental delay or disability.

Indicate to participants, as appropriate to your training session, that the native language of individuals with deafness, blindness, or no written language is considered to be the **mode of communication** is that normally used by the individual (such as sign language, Braille, or oral communication).

When there's no written language | Not mentioned on the slide but potentially very important to mention to your audience is what a public agency must do to provide understandable prior written notice when the parent's language is not a written one. IDEA requires that the public agency take steps to ensure:

- that the prior written notice is "translated orally or by other means" to the parents in their native language or other mode of communication;
- that the parent understands the notice; and
- that there is written evidence that these requirements have been met.²⁰

The Department noted that these rights "are essential to ensure that public agencies provide all parents the requisite prior written notice in a meaningful and understandable manner."²¹

Native language and the child in question | We won't go into how native language is defined for the babies and toddlers who enter the early intervention program for screening or evaluation and assessment, or those who are found eligible and begin receiving EI services. It's not relevant to this discussion of the prior written notice that must be provided to parents at given points in time.



References are given on the next page. ►

References

- ¹¹ §303.421(a)—Prior written notice and procedural safeguards notice: General.
- ¹² Douk, C., Douk, G., & Root, J.H. (1996). *Teaching patients with low literacy skills* (2nd ed.). Boston, MA: Harvard School of Public Health. See chapters 1-4, online at: <http://www.hsph.harvard.edu/wp-content/uploads/sites/135/2012/09/doakchap1-4.pdf>
- ¹³ Impact Information Plain Language Services. (n.d.). *Know your readers* (Plain Language at Work Newsletter). Retrieved June 25, 2014, from: <http://www.impact-information.com/impactinfo/literacy.htm>
- ¹⁴ Impact Information Plain Language Services. (n.d.). *Know your readers* (Plain Language at Work Newsletter). Retrieved June 25, 2014, from: <http://www.impact-information.com/impactinfo/literacy.htm>
- ¹⁵ Visit PlainLanguage.gov and find a wealth of materials and guidance on how to write in plain language. Connect with the 2010 plain language law (Public Law 111–274), training materials, and federal agency guidelines, all at: <http://www.plainlanguage.gov/>
- ¹⁶ Pandya, C., McHugh, M., & Batalova, J. (2011, December). *Limited English proficient individuals in the United States: Number, share, growth, and language diversity*. Washington, DC: Migration Policy Institute. Online at: <http://www.migrationpolicy.org/sites/default/files/publications/LEPdatabrief.pdf>
- ¹⁷ Ryan, C. (2013, August). *Language use in the United States: 2011* (ACS-22). Washington, DC: United States Census Bureau. Online at: <http://www.census.gov/prod/2013pubs/acs-22.pdf>
- ¹⁸ Dan. (2014, October 9). *The top 10 most popular languages in the US*. Retrieved December 17, 2014 from Accredited Language Services: <http://www.alsintl.com/blog/top-10-languages/>
- ¹⁹ 303.421(c)(1)—Prior written notice and procedural safeguards notice: Native language.
- ²⁰ 303.421(c)(2)—Prior written notice and procedural safeguards notice: Native language.
- ²¹ 71 Fed. Reg. at 46692.

When Parental Consent is Required



Opening View

Slide loads with the header "When Parental Consent is Required" and five pictures.

When Parental Consent is Required

<p>Before any screening procedures are used to determine if the child is suspected of having a disability</p>	<p>Before evaluation and assessment of the child</p>
<p>Before early intervention services are provided to the child</p>	<p>Before public benefits or insurance (or private insurance) are used (if consent is required)</p>
<p>Before personally identifiable information is disclosed</p>	

CLICKS 1-5

Clicks 1-5: Each time you click, one of the pictures will lift off and reveal the text beneath, giving an instance when parental consent is or may be required. Note that every item begins with the word "before."

CLICK AGAIN to advance to next slide.

See discussion on next page



Pertinent Handouts:

- Handout 7 | Parent Notification and Parent Consent
- Handout 16 | Summary Points of System of Payments and Use of Insurance in Part C (optional)

Here, we return to IDEA's requirements regarding parental consent. The importance of parental consent as a procedural safeguard was highlighted on Slide 4, in tandem with prior written notice. The definition of the term *consent* was also spotlighted on Slide 4.

The focus of the current slide is on the times when parental consent is or may be required. The slide is designed to be moved through quickly, if that's appropriate to your training session, or you can go more slowly, offering more information about each of the instances where parental consent is or may be required. Pull from the discussion below as you see fit.

Instance I: Before Screening

That picture over the quadrant for "screening" is.... uh... a screen. When you **CLICK** and the picture lifts away, you're left with the text beneath—thus, the first instance where parental consent is needed is "before any screening procedures are used to determine if the child is suspected of having a disability."

New option for States | For the first time, the Part C regulations expressly include provisions permitting States the option of "screening" children as part of operating a comprehensive child find system. The purpose of screening is to determine if an infant or toddler is suspected of having a disability and if the need for the more detailed, lengthy, and costly process of evaluation and assessment is indicated.

In States with screening procedures | Not every State will choose to adopt screening of children. (Does yours?) The bullet points below will apply only in States that adopt this option. If your State has not adopted screening as part of its child find process, then skip over this part.

- **Notice to parents** | If a lead agency or EIS provider wants to use screening to identify whether a child is suspected of having a disability, it must give parents the prior written notice discussed on the previous slide. That notice must also describe the parent's right to request an evaluation of the child at any time during the screening process.
- **Parental consent** | Parental consent is required before the child may be screened by the lead agency or EIS provider.
- **Parental right** | At any time during the screening process, parents may request an evaluation of their child. If they also provide their consent, the lead agency must provide the evaluation.
- **Results: Yes, a disability is suspected** | If the child is suspected of having a disability, a series of steps takes place: (1) The parent must be given notice of that determination. (2) The lead agency or EIS provider must ask for the parent's permission to conduct an evaluation and assessment of the child. (3) Parental consent for the evaluation and assessment must be obtained. (4) Only then may the evaluation and assessment of the child be conducted.
- **Results: No, a disability is not suspected** | If the child is not suspected of having a disability, the lead agency must provide notice of that determination to the parent. The notice must describe the parent's right to request an evaluation of the child. However, the lead agency is not required to provide an evaluation of the child unless the parent requests it and provides consent.
- **And if the parent so requests and consents?** | The regulations are clear: Even if the lead agency or EIS provider has determined that the child is not suspected of having a disability, it must

evaluate the child fully if the parent requests an evaluation and provides consent.

The dance of notice and consent | Note in this process how often the lead agency or EIS provider must provide prior written notice to the parents and how often it must obtain their consent before proceeding to the next step. This is an excellent illustration of what was depicted on Slide 4—prior written notice and the need for parental consent

very often go together. Both are important elements in protecting the rights of parents to be informed decision makers with respect to the Part C system's involvement with their child.

Where in the regulations? | Find the regulations for screening procedures at §303.320. The verbatim provisions appear in the box below.



§303.320 Screening procedures (optional).

(a) *General.* (1) The lead agency may adopt procedures, consistent with the requirements of this section, to screen children under the age of three who have been referred to the Part C program to determine whether they are suspected of having a disability under this part. If the lead agency or EIS provider proposes to screen a child, it must—

(i) Provide the parent notice under §303.421 of its intent to screen the child to identify whether the child is suspected of having a disability and include in that notice a description of the parent's right to request an evaluation under §303.321 at any time during the screening process; and

(ii) Obtain parental consent as required in §303.420(a)(1) before conducting the screening procedures.

(2) If the parent consents to the screening and the screening or other available information indicates that the child is—

(i) Suspected of having a disability, after notice is provided under §303.421 and once parental consent is obtained as required in §303.420, an evaluation and assessment of the child must be conducted under §303.321; or

(ii) Not suspected of having a disability, the lead agency or EIS provider must ensure that notice of that determination is provided to the parent under §303.421, and that the notice describes the parent's right to request an evaluation.

(3) If the parent of the child requests and consents to an evaluation at any time during the screening process, evaluation of the child must be conducted under §303.321, even if the lead agency or EIS provider has determined under paragraph (a)(2)(ii) of this section that the child is not suspected of having a disability.

(b) *Definition of screening procedures.* Screening procedures—

(1) Means activities under paragraphs (a)(1) and (a)(2) of this section that are carried out by, or under the supervision of, the lead agency or EIS provider to identify, at the earliest possible age, infants and toddlers suspected of having a disability and in need of early intervention services; and

(2) Includes the administration of appropriate instruments by personnel trained to administer those instruments.

(c) *Condition for evaluation or early intervention services.* For every child under the age of three who is referred to the Part C program or screened in accordance with paragraph (a) of this section, the lead agency is not required to—

(1) Provide an evaluation of the child under §303.321 unless the child is suspected of having a disability or the parent requests an evaluation under paragraph (a)(3) of this section; or

(2) Make early intervention services available under this part to the child unless a determination is made that the child meets the definition of infant or toddler with a disability under §303.21.

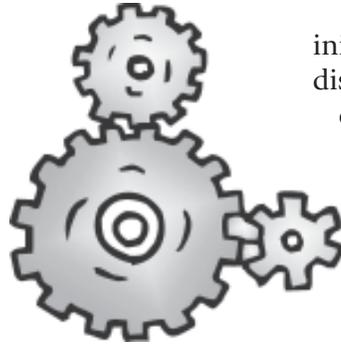
Instance 2: Before Evaluation and Assessment of the Child

When you **CLICK** again, the picture in the upper right will lift away and reveal another instance when parental consent is required: *Before evaluation and assessment of the child.*

Notice and consent again | If the lead agency or EIS provider would like to evaluate the child and conduct an assessment of his or her needs and strengths, prior written notice must be provided to that child's parents before the evaluation and assessment. Parental consent must also be obtained.

Summary of the evaluation and assessment process | In case you need to give a brief description of what evaluation and assessment in early intervention involve, here are several salient points:

- Evaluation and assessment are not the same thing, even though the terms are often used together. The Part C regulations define each term, as provided next.
- *Evaluation* means "the procedures used by qualified personnel to determine a child's initial and continuing eligibility."²²
- *Assessment* means "the ongoing procedures used by qualified personnel to identify the child's unique strengths and needs and the early intervention services appropriate to meet those needs throughout the period of the child's eligibility."²³
- Obviously, evaluation comes first, because it is used to determine a child's eligibility for Part C services. The only time that an evaluation isn't needed to establish eligibility is when a child's eligibility can be established by using the child's medical or other records.²⁴
- If parents consent to the assessment of their child, that assessment must include a review of the results of the evaluation conducted, personal observations of the child, and identification of the child's needs in five developmental areas.²⁵



What Happens if the Child is Not Found Eligible?

Let us suppose that the results of the child's initial evaluation indicate the child does not have a disability or a developmental delay or otherwise does not meet the State's definition of an "infant or toddler with a disability." What's important for participants to know about what happens next?

Informing the parents | The lead agency or EIS provider must give parents prior written notice as to their child's non-eligibility for Part C services. The notice must include information about the parent's dispute resolution rights under Part C of IDEA, which include the right to request a due process hearing or mediation or file a State complaint. (The dispute resolution mechanisms will be discussed in upcoming Slide 9.)

Is there a need to conduct an assessment of the child? | No. The child has not been found eligible for Part C.

What Happens if Parents Do Not Give Their Consent at Some Point?

Now let us suppose that parents decide *not* to consent to the screening of their child (if an option in the State), to the evaluation and/or assessment of their child, or to the provision of early intervention services to their child (the next instance on the slide, soon to be discussed). What can, should, or must the lead agency then do? What is it *not* permitted to do?

Must do | According to the Part C regulations, the lead agency must make **reasonable efforts** to ensure that the parent:

- is fully aware of the nature of the evaluation and assessment of the child or early intervention services that would be available; and
- understands that the child will not be able to receive the evaluation, assessment, or early intervention service unless consent is given.²⁶

May not do | The lead agency may *not* use the due process hearing procedures under IDEA to challenge a parent's refusal to provide any consent that is required in the circumstances listed on the

slide. In other words, the lead agency may *not* override the parents' refusal to provide consent for:

- screening of their child (if an option in the State);
- evaluation or assessment of their child;
- the provision of early intervention services to their child;
- the use of their public benefits or insurance (or private insurance) to pay for Part C services; or
- the disclosure of personally identifiable information.²⁷

Instance 3: Before Early Intervention Services Are Provided to the Child

With your third **CLICK**, the picture at the bottom left will lift away, and reveal another instance where parental consent is required: Before early intervention services are provided to the child.

Developing the IFSP | Once a baby or toddler is found eligible for Part C, an individualized family service plan (IFSP) must be developed for the child. Parents are part of the team that develops the IFSP, which documents key information, including (but not limited to):

- the child's current status (e.g., the child's present levels of development);
- family information (e.g., the family's resources, priorities, and concerns related to enhancing the development of their child);

- the outcomes or results expected to be achieved for the child and family; and
- the specific early intervention services that are necessary to meet the unique needs of the child and the family to achieve the results or outcomes.²⁸

Parental consent | The content of the IFSP must be fully explained to the parents, and their informed written consent must be obtained before any early intervention service described in the IFSP may be provided.²⁹ The Part C regulations requiring this can be found at §303.342(e) and appear in the left side of the box below.

But there's more! | The regulations just cited aren't the only ones that require parental consent before the provision of any early intervention services listed in the IFSP. In fact:

- Parental consent is required for before the initiation of each early intervention service.
- Parents determine whether they, their infant or toddler with a disability, or other family members will accept or decline any early intervention service at any time.
- Parents may decline a service after first accepting it, without jeopardizing other early intervention services.

Refer participants to **Handout 7** (page 2), where the regulations at §303.420 are provided verbatim. For your convenience, those provisions are given on the right side of the box below.

Parental Consent for the Provision of Early Intervention Services

(e) *Parental consent.* The contents of the IFSP must be fully explained to the parents and informed written consent, as described in §303.7, must be obtained, as required in §303.420(a)(3), prior to the provision of early intervention services described in the IFSP. Each early intervention service must be provided as soon as possible after the parent provides consent for that service, as required in §303.344(f)(1).

§303.420 Parental consent and ability to decline services.

(d) The parents of an infant or toddler with a disability—

(1) Determine whether they, their infant or toddler with a disability, or other family members will accept or decline any early intervention service under this part at any time, in accordance with State law; and

(2) May decline a service after first accepting it, without jeopardizing other early intervention services under this part.

Instance 4: Before public benefits or insurance (or private insurance) are used
(if consent is required)

When you **CLICK** again, the picture in the lower right will lift away, and reveal another instance when parental consent may be required: Before public benefits or insurance or private insurance may be used to pay for early intervention services.

Minimal explanation | This instance is complicated! It's also beyond the scope of this training module to fully explain the ins and outs of when the lead agency may use a parent's public benefits or insurance or private insurance as a means of paying for early intervention services. As a trainer, you may find it sufficient to help note these instances when parental consent may be required;

- understand it's a complicated issue and would be time-consuming to fully explain; and
- know where they might obtain more information about the use of a family's public benefits or insurance (or private insurance) to pay for early intervention services.

Maximum explanation | An entire training module is devoted to the use of funds in Part C—Module 14. A substantial part of that module looks specifically at the use of a family's insurance to pay for early intervention services—what's acceptable, when parental consent is required, what's not permitted, and so on. Feel free to draw from the information presented in Module 14 to elaborate here on Instance 4.

Summary points | Handout 16 provides a list of summary points about the use of funds in Part C, including the use of a family's insurance. Share the handout with participants if you wish, or merely share some of the following summary points made on the handout. For your convenience, we've captured these in the box on the next page.



Instance 5: Before personally identifiable information is disclosed

When you **CLICK** again, the picture at the very bottom of the screen (the pi sign) will move to the left and the following text (our last instance of when parental consent is required) will appear: Before personally identifiable information is disclosed.

Training suggestion | Again, this issue is complicated! Again, it's also beyond the scope of this training module to fully explain what Part C requires with respect to the collection, use, and disclosure of personally identifiable information (PII). Limit your treatment of this instance to the simple statement that parental consent is required before PII may be disclosed to unauthorized entities or parties.

Transitioning to the next slide | Limited discussion of this fifth instance of when parental consent is needed provides an excellent segue into the next slide, which focuses on the procedural safeguards associated with confidentiality and access to records.

References are given on page 26. 

Summary Points about Use of a Family's Insurance to Pay for Early Intervention Services

Parental consent for use of public benefits or insurance program

Public benefits or insurance program | A State may not require parents to sign up for or enroll in a public benefits or insurance program (e.g., Medicaid) as a condition of their child's receiving Part C services. A State may also not enroll a parent or child in such a program without parental consent.

Parental consent | The State must obtain parental consent before it may use a child or parent's public benefits or insurance to pay for Part C services if doing so would:

- decrease available lifetime coverage or any other insured benefit of the child or parent;
- result in the parents paying for services that would otherwise have been paid for by the public program;
- result in any increase in premiums or cancellation of the public benefits or insurance program for the child or parents; or
- risk the loss of eligibility for the child or parents for home and community-based waivers based on total health-related costs.

Parent right and State responsibility | If a parent does not provide consent for the use of the child's or parent's public benefits or insurance, the State lead agency must still make all Part C services on the IFSP available to the child and family (subject to the State's system of payments, if applicable).

Written notification | When a State uses a child's or parent's public benefits or insurance to pay for Part C services, the State must provide written notification to the parent. The



notification must include specific information, including that:

- parental consent is required before a child's personally identifiable information (PII) may be disclosed (for billing purposes) to the State agency responsible for administering the public benefits or insurance program (unless the lead agency for Part C also administers the public program or chooses to require parental consent in this circumstance;)
- parents have the right to withdraw their consent at any time for this disclosure of their child's PII for billing purposes; and
- the general categories of costs to parents for participating in the public benefits or insurance program (e.g., copays or deductibles, or the required use of private insurance as the primary insurance).

Parental consent for use of private insurance

Use of private insurance—parental consent | A parent must provide consent for the use of his or her private insurance (unless the one exception identified below applies).

Repeated parental consent | Parental consent must be obtained:

- before a parent's private insurance or benefits may be accessed to pay for the initial provision of an early intervention service listed in the IFSP; and
- each time there's an increase (in frequency, length, duration, or intensity) in the provision of services in the child's IFSP.

These summary points are continued on the next page. 

Drawn from Handout 16

**Summary Points about Use of a Family’s Insurance
to Pay for Early Intervention Services**

When parental consent is not required | Parental consent isn’t required if the State has passed a statute regarding private health insurance coverage for Part C services and that statute expressly provides that the use of the parent’s private insurance for Part C:

- cannot count toward or result in the loss of benefits due to annual or lifetime coverage caps for the child, parent, or family members covered by the insurance policy;
- cannot negatively affect the availability of health insurance to the child, parent, or covered family members or result in the discontinuation of the insurance for these individuals; and
- cannot be the basis for increasing the premiums of the child, parent, or covered family members.

System of Payments | If the State requires a parent to use private insurance to pay for Part

C services and doing so will result in costs to the parent (e.g., copayments or deductibles), those general types of costs must be included in the State’s system of payments or the State may not charge those costs to parents.

Informing Parents | When obtaining parental consent to use private insurance (if such consent is required), the State must give parents a copy of its system of payment policies that identify the potential costs that parents may incur as a result of using their private insurance to pay for Part C service.

Final summary point

The Part C regulations require States to inform parents that mediation, due process, and the State complaint process are available as dispute resolution mechanisms if a parent wishes to contest a fee or the State’s determination of the parent’s ability to pay.

References

- ²² §303.321(a)(2)(i)—Evaluation of the child and assessment of the child and family: General.
- ²³ §303.321(a)(2)(ii)—Evaluation of the child and assessment of the child and family: General.
- ²⁴ §303.321(a)(3)(i)—Evaluation of the child and assessment of the child and family: General.
- ²⁵ §303.321(c)—Evaluation of the child and assessment of the child and family: Procedures for assessment of the child and family.
- ²⁶ §303.420(b)—Parental consent and ability to decline services.
- ²⁷ §303.420(c)—Parental consent and ability to decline services.
- ²⁸ §303.344—Content of an IFSP.
- ²⁹ §303.342(e)—Procedures for IFSP development, review, and evaluation: Parental consent.

Two More Procedural Safeguards



Parental right to confidentiality of personally identifiable information



Parental right to inspect and review their 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 14** | Summary Points of Part C's Confidentiality Provisions (*optional*)
- **Handout 15** | Part C's Confidentiality Provisions (verbatim) (*optional*)

Moving on from the procedural safeguard of a parent's right to give or refuse consent in early intervention, let's look at two other important procedural safeguards. In both cases, a separate training module is available to provide in-depth information, so what is presented here, in this module, is meant to be introductory. Should you wish to offer more detail about either of the two procedural safeguards addressed on this slide, consult Module 12, *Access to and Examination of Records*.

About Handouts 14 and 15 | To augment this introduction to the two procedural safeguards highlighted on the slide, you may wish to provide participants with Handouts 14 and 15. **Handout**

14 gives summary points about confidentiality in Part C, while **Handout 15** provides the relevant Part C regulations, verbatim.

Confidentiality of Personally Identifiable Information

The left part of the slide identifies that parents have the right to confidentiality of personally identifiable information. **Handout 15** provides the Part C regulations regarding confidentiality. Summary points you might make regarding this right can be found on **Handout 14** and include the following information.

The context | In order to provide services to infants and toddlers and their families under Part C, the lead agency and its EIS providers commonly collect information about the infant or toddler and the child’s family. This includes (but isn’t limited to) personally identifiable information such as the child’s name, date of birth, disability, and records relating to evaluations and assessments, screening, eligibility determinations, and provision of early intervention services.

The procedural safeguards | Parents have the right to confidentiality of this personally identifiable information, which includes the right to be provided with written notice of any intended exchange of that PII among agencies. Parents also have the right to provide or decline their consent to disclosures of their PII to unauthorized individuals or agencies, as summarized below.

Where in the regs? | Part C’s confidentiality provisions can be found in the Part C regulations—specifically, at §303.401—§303.417. The entire section is entitled “Confidentiality of Personally Identifiable Information and Early Intervention Records.”

How is “personally identifiable information” defined? | Part C draws its definition of PII from 34 CFR 99.3, which are the regulations of FERPA, the Family Educational Rights and Privacy Act. FERPA’s definition is then adapted so that Part C’s definition of PII refers to infants and toddlers with Part C. Making those adjustments, then, PII 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;
- 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.

State responsibility | Each State must have procedures to ensure that participating agencies (including the lead agency and EIS providers) are trained in, and comply with, Part C’s confidentiality provisions.

What’s a participating agency? | *Participating agency* is defined as any individual, agency, entity, or institution that collects, maintains, or uses PII with respect to a particular child in Part C. 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.

However, *participating agency* does not include primary referral sources, 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.

Informing parents | When a child is 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. The notice includes (but is not limited to) such information as what type of PII is collected and what procedures participating agencies are required to follow regarding its storage, disclosure to third parties, retention, and destruction.

For how long? | The confidentiality provisions apply from the point in time when the child is referred for early intervention services until the participating agency is no longer required to maintain or no longer maintains that information under applicable Federal and State laws (whichever comes later).



Parent consent for disclosure of PII | With limited exceptions, parental consent must be obtained before PII may be disclosed to anyone other than authorized representatives, officials, or employees of participating agencies collecting, maintaining, or using the information.

Access to and Examination of Records

The right part of the slide identifies that parents have the right to inspect and review their child's early intervention records. As mentioned above, this subject is addressed in detail in Module 12. Here, in this module, you may wish to make the following summary points about this important procedural safeguard.

Parent right | The Part C regulations give the parents of a child referred to, or served under, Part C the right to inspect and review all early intervention records about their child and family that are collected, maintained, or used in Part C. Parents also have the right to a response from the

agency to reasonable requests for explanations and interpretations of the information contained in those records.

Where in the regs? | This procedural safeguard appears at §303.405, which is provided on **Handout 15** and in the box below.

What if parents believe something's not correct in those records? | What happens if parents find something in their child's early intervention records they believe is inaccurate or misleading or that violates their privacy rights, or the privacy rights of their child. Part C gives parents the right to request that the participating agency that maintains the information amend the information.

The agency's response | The agency must decide within a reasonable period of time whether or not it is going to amend the information in question as requested by the parents. If it agrees, it must do so and inform the parents. If the agency refuses, however, then it must notify parents of that decision and let parents know they have the right to ask for a hearing.

If a hearing occurs | The point of a hearing in this circumstance is to have a third and impartial party (the hearing officer) determine whether or not the information in the child's early



§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.

intervention records is, indeed, inaccurate, misleading, or violates privacy or other rights of the parents or child.

- If the determination is **yes**, then the agency must amend the child's records accordingly and inform the parents that it has done so.
- If the determination is **no**, the agency must let the parents know that they have the right to place a statement in their child's early intervention records commenting on the information or setting forth any reasons for disagreeing with the decision of the agency.

Not one without the other | 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 records (or all the records, for that matter) are shared with any other party, then the parents' statement must also be shared. Not one without the other.

There's more to the story | Module 12 covers this procedural safeguard in some detail. Lest the summary here fall short of what participants need or want to know, we wish to reiterate that the above information doesn't cover all the particulars.

Not mentioned, for example, are aspects such as how quickly the agency must respond to a parent's request to inspect and review early intervention records, whether the agency can charge parents to retrieve the records, whether parents may ask for copies, whether the agency can charge for the copies, and more. If participants need to know this information, consult Module 12 for the specific details and refer participants to the verbatim regulations that appear on **Handout 15**.

Appointing a Surrogate Parent

If needed to protect the rights of an infant or toddler with a disability, a surrogate parent may be appointed, when:



- No parent can be identified for the child
- The lead agency or other public agency, after reasonable efforts, cannot locate the child's parent, or
- The child is a ward of the State under State law

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CLICK to advance to next slide.

Pertinent Handout:

- Handout 17 | Procedural Safeguard: Appointing a Surrogate Parent for a Child

In some situations, it may be necessary for the lead agency or other public agency to appoint a surrogate parent to ensure that the rights of an infant or toddler with a disability are protected. As the slide indicates, this occurs when:

- no parent can be identified for the child; or
- the lead agency or other public agency, after reasonable efforts, cannot locate a parent; or
- the child is a ward of the State under the laws of that State.

Agency Responsibility

To address any of these circumstances, the lead agency or other public agency must have a process in place that includes a method for determining whether a child needs a surrogate parent, and for assigning a surrogate parent to the child.

What's a Surrogate Parent?

Generally speaking, a surrogate parent represents and makes decisions on behalf of a child under Part C of the IDEA when there is no "parent" who can be found and the definition of who can act as a "parent" under IDEA Part C is broad. Both IDEA and State law are factors in determining the specifics of who may serve as a surrogate parent, how that person is selected, and what that person's responsibilities are.

Criteria for Selecting a Surrogate Parent

The lead agency or other public agency may select the surrogate parent in any way permitted under State law.³⁰ This means that there will be some variation from State to State in selection criteria for surrogate parents and the process associated with appointing a surrogate parent. What the Part C regulations make clear, however,

are several *restrictions* on who may be appointed as a child’s surrogate parent. These restrictions are found at §303.422(d) (see the box on the next page and **Handout 17**). In short, the public agency must ensure that a person selected as a surrogate parent:

- is *not* an employee of the lead agency or any other public agency or EIS provider that provides early intervention services, education, care, or other services to the child or any family member of the child;
- has no personal or professional interest that conflicts with the interest of the child he or she represents; and
- has knowledge and skills that ensure adequate representation of the child.³¹

A person who is otherwise qualified to be a surrogate parent under these requirements is not an employee of the agency solely because he or she is paid by the agency to serve as a surrogate parent.³²

Rights of a Surrogate Parent

IDEA’s regulations indicate that, once appointed, a surrogate parent has the same rights as a parent in Part C.³³

Is the Child a Ward of the State or in Foster Care?

When the lead agency implements its policies and procedures for appointing a surrogate parent, the process may be a bit different when the child involved is a ward of the State or in foster care. According to the Part C regulations, when this is the case, “the lead agency must consult with the public agency that has been assigned care of the child.”³⁴

Statistics on Numbers of Children in Foster Care

On September 30, 2012, there were approximately 82,630 children younger than 3 years old in foster care in the United States.³⁵

When the Child is a Ward of the State

If the child in question is a ward of the State, the lead agency is not necessarily the entity that appoints a surrogate parent for the child. In this case, the surrogate parent may be appointed by the judge overseeing the infant or toddler’s case, as long as the surrogate appointed by the judge meets the criteria discussed above (i.e., the restrictions on who may be appointed as a surrogate).

Timelines for Assigning a Surrogate Parent

New in the 2011 Part C regulations! The lead agency must make reasonable efforts to ensure the assignment of a surrogate parent **not more than 30 days after** a public agency determines that the child needs a surrogate parent.³⁶ As the Department notes in its *Analysis of Comments and Changes*:

Given that the development of infants and toddlers quickly changes, identifying a surrogate parent in a timely manner is important to a child, prevents undue delays, and aids the effective implementation of the requirements of this part.³⁷

References are given on page 34. 

§303.422 Surrogate parents.

(a) *General.* Each lead agency or other public agency must ensure that the rights of a child are protected when—

(1) No parent (as defined in §303.27) can be identified;

(2) The lead agency or other public agency, after reasonable efforts, cannot locate a parent; or

(3) The child is a ward of the State under the laws of that State.

(b) *Duty of lead agency and other public agencies.* (1) The duty of the lead agency, or other public agency under paragraph (a) of this section, includes the assignment of an individual to act as a surrogate for the parent. This assignment process must include a method for—

(i) Determining whether a child needs a surrogate parent; and

(ii) Assigning a surrogate parent to the child.

(2) In implementing the provisions under this section for children who are wards of the State or placed in foster care, the lead agency must consult with the public agency that has been assigned care of the child.

(c) *Wards of the State.* In the case of a child who is a ward of the State, the surrogate parent, instead of being appointed by the lead agency under paragraph (b)(1) of this section, may be appointed by the judge overseeing the infant or



toddler's case provided that the surrogate parent meets the requirements in paragraphs (d)(2)(i) and (e) of this section.

(d) *Criteria for selection of surrogate parents.* (1) The lead agency or other public agency may select a surrogate parent in any way permitted under State law.

(2) Public agencies must ensure that a person selected as a surrogate parent—

(i) Is not an employee of the lead agency or any other public agency or EIS provider that provides early intervention services, education, care, or other services to the child or any family member of the child;

(ii) Has no personal or professional interest that conflicts with the interest of the child he or she represents; and

(iii) Has knowledge and skills that ensure adequate representation of the child.

(e) *Non-employee requirement; compensation.* A person who is otherwise qualified to be a surrogate parent under paragraph (d) of this section is not an employee of the agency solely because he or she is paid by the agency to serve as a surrogate parent.

(f) *Surrogate parent responsibilities.* The surrogate parent has the same rights as a parent for all purposes under this part.

(g) *Lead agency responsibility.* The lead agency must make reasonable efforts to ensure the assignment of a surrogate parent not more than 30 days after a public agency determines that the child needs a surrogate parent.

References



- ³⁰ §303.422(d)(1)—Surrogate parents: Criteria for selection of surrogate parents.
- ³¹ §303.422(d)(2)—Surrogate parents: Criteria for selection of surrogate parents.
- ³² §303.422(e)—Surrogate parents: Non-employee requirement; compensation.
- ³³ §303.422(f)— Surrogate parents: Surrogate parent responsibilities.
- ³⁴ §303.422(b)(2)—Surrogate parents: Duty of lead agency and other public agencies. *Note:* Under the Uninterrupted Scholars Act amendments to FERPA, this consultation may occur without the need to obtain parental consent. See *Guidance on the Amendments to the Family Educational Rights and Privacy Act by the Uninterrupted Scholars Act*:
<http://www2.ed.gov/policy/gen/guid/fpco/ferpa/uninterrupted-scholars-act-guidance.pdf>
- ³⁵ Children's Bureau, U.S. Department of Health and Human Services. (2013, November). *Preliminary FY2012 estimates as of November 2013* (AFCARS Report #20). Washington, DC: Author. (AFCARS stands for the Adoption and Foster Care Analysis and Reporting System.) Online at:
<http://www.acf.hhs.gov/sites/default/files/cb/afcarsreport20.pdf>
- ³⁶ §303.422(g)—Surrogate parents: Lead agency responsibility.
- ³⁷ 76 Fed Reg. at 60214.

A Look from Outer Space at...

Part C's Dispute Resolution Options



Opening View

Slide loads with this view.

A Look from Outer Space at...

Part C's Dispute Resolution Options

- Mediation
- State complaint



- Due process hearing



Click 1

Click 1:
The picture of the astronaut lifts away, and the 3 dispute resolution options automatically appear.

CLICK AGAIN to advance to next slide.

See discussion on next page 



Pertinent Handouts:

- Handout 18 | Summary Points—Dispute Resolution Options in Part C
- Handout 19 | (optional) Verbatim Regulations—Dispute Resolution Options in Part C

The dispute resolution options comprise another important procedural safeguard for families and early intervention systems alike. The dispute resolution options provide a means for parents, lead agencies, and EIS providers to resolve disputes arising under Part C. By the very word “options,” you can tell that there are several mechanisms available by which to resolve disputes.

Dispute Resolution Options under Part C of IDEA

Each State’s early intervention system must include written procedures for the timely administrative resolution of complaints through the three options listed on the slide:

- mediation,
- State complaint procedures, and
- due process hearing procedures.

A brief description of each option is provided below. Be sure to point out to the audience that this slide’s discussion is an *introduction only* to the dispute resolution options in Part C.

Mediation

Each lead agency must make the opportunity for mediation available to parties in disputes involving any matter under Part C. Part C’s regulations and requirements regarding mediation can be found at §303.431. **Handout 18** provides a list of summary points about the mediation process.

Each lead agency must ensure that procedures are established to allow parties to disputes to resolve their dispute through mediation. Summarizing what’s required in terms of those procedures, you might mention the following:

- Mediation is voluntary on the part of the disputing parties.



Trainer’s Note: What about the Regs?

The verbatim regulations for the dispute resolution options in Part C are presented in **Handout 19**. We make the handout available for you to share with participants, if you feel they would benefit from having the full regulations in writing for later reference.

However, **Handout 19**—which is 12 pages long—is likely to be “TMI” (too much information) for most participants just beginning to learn about Part C’s procedural safeguards.

- Mediation may not be used to deny or delay a parent’s right to a due process hearing or to deny any other rights under Part C.
- Mediation is conducted by a qualified and impartial mediator who is trained in effective mediation techniques. The mediator helps the parties come to agreement.
- If an agreement is reached, the parties write a legally binding agreement that sets forth their resolutions. Both parties sign the agreement, which must remain confidential and may not be used as evidence in any later due process hearing or civil action.
- The State bears the cost of the mediation process.³⁸



State Complaint Procedures

Each lead agency must adopt procedures to resolve any State complaints filed by any party regarding any violation of Part C. Those procedures must meet the requirements stated in §303.432 through §303.434. **Handout 18** provides a list of summary points of those requirements.

In discussing State complaint as a dispute resolution option, consider sharing the following requirements. *Do* make it clear to participants that this information is a *summary of the “high points” only* and that there are details and finer points that won’t be discussed here.

Who may file a State complaint | A State complaint may be filed by an organization or an individual, including from another State.

What must be included | A State complaint that’s filed must include specific information and be signed.

Time limit and steps involved in resolving the complaint | Each lead agency has a time limit of 60 days after the complaint is filed to respond to the complaint. Its response typically includes:

- carrying out an on-site investigation (if the lead agency believes that’s necessary);

- giving the party who filed the complaint (known as the *complainant*) the opportunity to submit more information about his or her allegations;
- giving the lead agency (or public agency or EIS provider) the opportunity to respond to the complaint;
- giving the parties the opportunity to engage in mediation;
- reviewing all relevant information and making an independent determination regarding the veracity of the complaint; and
- issuing a written decision, including findings of fact and conclusions, the reasons for the lead agency’s final decision, and appropriate corrective actions.

The time limit may be extended under exceptional circumstances or if the parties agree to extend the time so that they may engage in mediation.

Due Process Hearing Procedures

Each lead agency must adopt procedures to resolve due process complaints with respect to a particular child regarding any matter under Part C. You’ll find Part C’s regulations for due process at §303.345 through §303.445.

Which due process procedures to use? | Interestingly, the lead agency has the option of adopting the due process procedures from either Part C or Part B of IDEA. So it’s important to know which set of procedures your State had chosen to adopt in terms of due process.

According to the Department’s *Analysis of Comments and Changes*, the vast majority of States use, and will likely continue to use, the Part C due process procedures instead of exercising the option to use the Part B procedures. This is in part because the Part B due process procedures contain additional steps and procedures.³⁹

Summary points | That said, here’s a summary of what’s generally involved in due process. Refer participants to **Handout 18**, reminding them that the information there is only a summary, not the full story with all the glorious details!

- Due process complaints may be filed by a parent, EIS provider, or lead agency.
- Due process complaints may cover issues related to identification, evaluation, or placement of a child, or the provision of EI services under Part C.
- If a due process complaint is not resolved through mediation (or, in Part B, in a resolution session), the dispute is resolved in a due process hearing.
- Parents have specific rights in a due process hearing, including the right to be accompanied and advised by counsel and other qualified individuals. They also have the right to present evidence, and to confront, cross-examine, and compel the attendance of witnesses and the right to receive at least five days before the hearing any anticipated evidence that was not disclosed to them.
- An impartial hearing officer oversees the due process hearing and issues a hearing decision, which includes findings of fact, conclusions, and corrective actions.
- Parents have the right to obtain a written or electronic verbatim transcript of the hearing, provided at no cost to them. They also have the right to receive a written copy of the hearing officer's findings of fact and decisions at no cost.



- The hearing officer's decision is appealable to civil court, and in some cases, to the lead agency.
- The requirements for lead agencies, and the rights of the parties, vary based on whether the State has adopted Part C or Part B due process procedures. For example, in States adopting Part B due process procedures, a resolution process is triggered when a parent files a due process complaint. This is one of the "additional steps" in Part B's due process procedures mentioned earlier.

Timelines | In States adopting Part C's due process procedures, the lead agency must ensure that the due process hearing is completed and a written decision is mailed to each of the parties no later than 30 days after receiving the parent's due process complaint. States using Part B's procedures must specify in their policies whether they will use Part B's 45-day timeline or the shorter 30-day timeline specified for Part C.

Stay put | An important procedural safeguard, commonly referred to as "stay put," is triggered when a due process complaint is filed. Specifically, during the pendency of any proceeding involving a due process complaint, unless the lead agency and parents of an infant or toddler with a disability agree otherwise, the child must continue to receive the appropriate early intervention services in the setting identified in the IFSP that is consented to by the parents. If the due process complaint involves an application for initial services under part C, the child must receive those services that are not in dispute.

References

³⁸ §303.431—Mediation.

³⁹ 76 Fed. Reg. at 60217.



Round-Up Time!

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Pertinent Handout:

- Activity Sheet 14 | Reflecting on Part C's Procedural Safeguards

You've done it, you're through with this module! Well, almost...

Depending on how much time you still have available for your training session, you can use this slide:

- for a quick review and recap of your own devising;
- to open the floor up for a question and answer period;
- by having participants complete a closing activity of your choice and discuss in the large group afterwards; or
- to share **Activity Sheet 14** with participants, described in the box to the right.

Questions Asked on Activity Sheet 14

1. List at least 3 procedural safeguards provided by the Part C regulations. (No peeking at your notes or handouts!)

2. In one or two sentences, what value or significance do Part C's procedural safeguards bring to early intervention systems and the individuals involved in early intervention?

3. You heard about several important procedural safeguards in Part C. To you, which seems the most important? Why?

4. How are procedural safeguards relevant to you personally or professionally? Name at least 1 way you can see using this information after today.

Optional Activity

Total Time Activity Takes: 15 minutes.

Group Size: Individual, then large group

Materials: Activity Sheet 14, Reflecting on Part C's Procedural Safeguards

Instructions

1. Refer participants to **Activity Sheet 14**. 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.

2. In the large group, have different participants share their answers to the questions and why they gave those answers. Allow dialogue between participants, too.

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National Dissemination Center for Children with Disabilities

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Funding for NICHCY officially ended on September 30, 2014. All training materials in this Part C training curriculum are now available at the website of the Center for Parent Information and Resources, at:

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