

Introduction to Procedural Safeguards



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Much of the code and regulation cited in this Handbook has been paraphrased for clarity and conciseness. For the full text of legislative code and regulation, refer online to the citation provided.

Notes:

KEY CONCEPTS OF PROCEDURAL SAFEGUARDS

- Parental consent is required before evaluation, assessment, and initiation of services and before information is disclosed by the regional center or local educational agency (LEA) to agencies or individuals outside the regional center or LEA.
- Parents are not required to give consent and may withdraw their consent at any time.
- Parents have the right to inspect any records in their child's file.
- The confidentiality of the infant or toddler's and their family's personally identifiable information must be protected.
- Procedural safeguards extend to individuals acting legally as parents.

Notes:

OVERVIEW OF PROCEDURAL SAFEGUARDS

What Are Procedural Safeguards?

Procedural safeguards are measures taken to ensure protection of the rights and information of infants, toddlers, and families during their Early Start experience. These safeguards inform parents of their rights and describe the service coordinator's responsibilities for protecting these rights while a child is enrolled in Early Start.

Early Start procedural safeguards address the following:

- Protection of personally identifying information
- Written notice
- Informed consent
- Right of parents to access records
- Surrogate parents
- Complaint process
- Mediation and due process for resolving disputes

Procedural safeguards protect the interests of both families and children and the early intervention service system by providing procedures for and documentation of interactions with families about critical decisions and service delivery. This chapter covers the procedural safeguards in the first five areas listed above; they are primarily preventative in nature. Some procedural safeguards come into play only after disagreements or disputes arise. Chapter 9, Mediation and Due Process, of this Handbook covers procedural safeguards related to complaints and dispute resolution.

The procedural safeguards for all Part C early intervention programs are codified in the Individuals with Disabilities Education Act (IDEA) Part C, Title 34, Code of Federal Regulations (CFR), Sections 303.400 through 303.449. Procedural safeguards for California’s Early Start program are found in Title 17, California Code of Regulations (CCR), Division 2, Chapter 2. These regulations are cited throughout this chapter.

What Is Confidentiality?

The regional center or LEA must have methods to protect the confidentiality of personally identifiable information for the child and family, including:

- From whom information is gathered;
- How information will be used;
- How information will be stored, disclosed, retained, or destroyed; and
- Parents’ right to access information.

Title 17 CCR Section 52160(c)

What Is Personally Identifiable Information?

Personally identifiable information maintained by the regional center or LEA about a child, parent, or other family member includes:

- Full names;
- Addresses;
- Personal identifiers, such as social security numbers; and
- Lists of personal characteristics or other information that would make it possible to identify the infant or toddler or family member with reasonable certainty.

Title 17 CCR Section 52000(b)(46)

SERVICE COORDINATOR RESPONSIBILITIES

Service coordinators must:

- Provide written initial and annual notice to parents;
- Obtain consent for evaluation, assessment, and initiation of services;
- Provide written notice of changes proposed or refused by a regional center or LEA; and
- Inform parents about advocacy services and procedural safeguards available to protect their rights and the rights of their child.

Title 17 CCR Section 52121(a)(1, 2, 10)

Initial and Annual Notice

Prior to a child's initial evaluation to determine eligibility and assessment for program development and monitoring, and every year thereafter, service coordinators must provide written notice to the parent.

Procedures for Initial and Annual Notice

The notice must include:

- The personally identifiable information maintained by the regional center or LEA;
- The types of information used in the evaluation, assessment, and individualized family service plan (IFSP) development; and
- The methods that regional centers and LEAs use to protect the confidentiality of personally identifiable information including:
 - The sources from whom personally identifiable information is gathered;
 - The uses to be made of the personally identifiable information;
 - The policies and procedures that regional centers and LEAs follow regarding storage, disclosure to third parties, retention, and destruction of personally identifiable information as required in Title 34 CFR, Sections 300.572 through 300.573; and

- The rights of parents, infants, and toddlers regarding access to information, including the rights accorded to families in these regulations and the rights under the Family Education Rights and Privacy Act of 1974, Title 20, United States Code (USC), Section 1232(g) and implementing regulations in Title 34 CFR, Section 99.

Title 17 CCR Section 52160

General Notice

Timeline for General Notice

Written notice must be given to the parent of an infant or toddler eligible or suspected to be eligible to receive early intervention services a reasonable time before a regional center or LEA proposes, or refuses, to initiate or change the following:

- Identification
- Evaluation
- Assessment
- Placement
- Early intervention services

Title 17 CCR Section 52161(a)

Procedures for Written Notice

The notice must be in sufficient detail to inform the parent about:

- The action being proposed or refused;
- The reasons for taking or refusing the action; and
- All procedural safeguards available under Title 34 CFR, Sections 303.400 through 303.449 (Part C of IDEA).

Title 17 CCR Section 52161(b)

The notice must be understandable to the general public and provided in the language of the parent's choice unless clearly not feasible.

Title 17 CCR Section 52161(c)(1)

The regional center or LEA must also take steps to ensure that the notice is translated, that the parent understands the notice, and that there is written evidence that the requirements of Title 17 CCR Section 52161(c) have been met.

Title 17 CCR Section 52161(c)(2)

Informed Consent

Parental consent is required before several steps in the IFSP process, including evaluation and assessment and the start of early intervention services. Consent is voluntary and may be revoked at any time.

Timelines for Consent

Written parental consent must be obtained before personally identifiable information is disclosed in writing or orally to anyone other than authorized employees specified by the regional center or LEA.

Title 17 CCR Section 52169

Written parental consent must be obtained:

- Before the child's initial evaluation and assessment are conducted;
- Before early intervention services are initiated following IFSP development or review;
- Before information is disclosed verbally or in writing to anyone other than authorized employees specified by the regional center or LEA.

Title 17 CCR Sections 52162(a) and 52169

Procedures for Consent

Parents must be informed about the evaluation, assessment, or services that require their consent as well as their right to revoke consent or decline services.

The infant's or toddler's record must include written evidence that the parent has been informed:

- Of information relevant to the evaluation, assessment, early intervention service, or exchange of records for which consent is sought, in the language of the parent's choice, and that the parent agrees to the completion of the evaluation and/or assessment and the provision of early intervention services;
- That consent is voluntary and may be revoked at any time;
- That the parent may accept or decline any early intervention service, may decline such service after first accepting it, and may continue to receive other early intervention services; and
- Regarding who will receive the records and a listing of the records to be exchanged.

Title 17 CCR Section 52162(b)

Right to Withdraw or Refuse Consent

Parents have the right not to give consent or withdraw their consent after services have begun. If consent is not given or is withdrawn, the service coordinator must ensure that:

- The parent has been informed of the nature of the evaluation and assessment and/or the early intervention service(s) that would have been provided;
- The parent has been informed that the infant or toddler will not receive the evaluation and assessment or early intervention service(s) unless consent is given; and
- Attempts to obtain consent are documented in the infant or toddler's record.

The child and family must continue to receive other early intervention services that have not been declined.

Records and Access Rights

Parents have the right to inspect and review any record related to their infant or toddler. A parent's authority to inspect and review their child's record must be presumed unless there is a court order, state statute, or legally binding document that specifically revokes those rights.

Title 17 CCR Section 52164(a)(d)

Regional Centers and LEAs Must Document Access to Records

When granting access to a child's record, maintain documentation specifying to whom the record was disclosed other than parents and authorized employees.

Documentation of access shall include:

- The name of the person to whom the record was disclosed;
- The date the record was disclosed; and
- The purpose for which the record was disclosed.

Timelines for Requests for Access to a Child's Record

If a parent requests access to their child's record, the request must be granted as soon as possible but no more than five working days after the request has been received by the regional center or LEA.

Title 17 CCR Section 52164(b)

Procedures for Requests for Access to a Child's Record

Requests from parents for explanations and interpretations of the content of a record must be granted.

Title 17 CCR Section 52164(c)

Provide parents, on request, a list of the types and locations of records collected or used by the regional center or LEA;

Title 17 CCR Section 52164(e)

If a record includes information about more than one infant or toddler, the parent may:

- Inspect or review only the information relating to their child; or
- Be informed of that specific information.

Title 17 CCR Section 52166

Fees

- Regional centers or LEAs may charge for copies of records but the fee may not exceed the actual copying cost.
- Fees shall not prevent parents from exercising their right to inspect and review records.
- A fee may not be charged to search for or retrieve records.

Title 17 CCR Section 52167

Requesting Amendments to the Child's Record

If requested by a parent who wishes to amend or remove information that originated outside the regional center or LEA from their child's file, assist the parent in communicating with those who created information contained in the record.

Title 17 CCR Section 52168(b)

Parents have the right to request that information in their child's record be removed or amended if the parent believes that the information is inaccurate or misleading or violates a child's or family's privacy or rights.

Title 17 CCR Section 52168(b)

The regional center or LEA must accept or deny the request and notify the parent of its decision within 14 days.

Title 17 CCR Section 52168(c)

NOTE: “Day” means calendar day unless otherwise stated.

Title 17 CCR Section 52000(b)(14)

If a parent’s request to remove or amend information in their child’s record is denied, the parent has the right to a meeting with the director of the regional center or the superintendent of the LEA.

Title 17 CCR Section 52168(c)

If the result of the meeting with the director or superintendent is that the record will not be amended, the parent has the right to place in their child’s record a statement commenting on the information in the record or expressing any reasons for disagreeing with the contents the record, regardless of who created the document. The statement must:

- Be kept in the record of the infant or toddler as long as the contested portion of the record is maintained by the regional center or LEA; and
- Accompany the record of the infant or toddler if the contested portion is disclosed by the regional center or LEA.

Title 17 CCR Section 52168(d)–(e)

Surrogate Parents

Individuals may act as surrogate parents to an infant or toddler receiving Early Start services. A surrogate parent is not the same as a parent or legal guardian, and their rights and responsibilities differ from that of a parent or guardian.

Regional centers and LEAs must assign an individual to act as a surrogate parent if:

- No parent can be identified;
- The infant or toddler is a dependent of the juvenile court and parental rights have been limited or removed by the court or relinquished by the parent; or
- The parent cannot be located, after reasonable efforts.

Title 17 CCR Section 52175(a)

A surrogate parent **may** represent an infant or toddler in all matters related to:

- Evaluation and assessment;
- Development and implementation of the IFSP including annual evaluations, assessments, and periodic reviews;
- Ongoing provision of early intervention services;
- Requesting mediation or due process hearings; and
- Any other early intervention service established under Part C of IDEA.

A surrogate parent **may not** provide consent for medical services for which consent by a parent or legal guardian is required.

Title 17 CCR Section 52175(c)(d)

QUALITY PRACTICES

The following procedural safeguard practices are adapted from articles on the Early Childhood and Technical Assistance Center and the National Early Childhood and Technical Assistance Center websites.¹

During Intake

- Show the family the location of the procedural safeguards written in the program materials and tell them that you will review these at different points in the IFSP process.
- When explaining confidentiality, help parents to understand how and when information is shared within the program.
- Help parents understand how and when information might be shared outside the program, with their approval. Explain that, just as the early intervention program cannot share information about the family without permission, it also needs the family's permission to ask other programs for information about their child and the family.
- Understand the need to explain additional safeguards in place to protect confidentiality according to other local, state, or federal laws. In particular, explain to parents their confidentiality protections according to the Family Education Rights and Privacy Act (FERPA).
- Keep records in a secure location and limit access to only those team members who are necessary to provide services.

During Evaluation and Assessment

- Describe the kinds of information that will be important in the evaluation and assessment processes. Explain prior notice and review all the rights and procedural safeguards with the family, asking if they have any questions such as, "Is this clear and understandable?" "Do you have any questions about why we need to do it this way?"

After Eligibility Is Established

- Before an IFSP meeting, prepare the family with information about what an IFSP is, what will happen, what will be decided, how it will be decided, and who will or can be present at the IFSP meeting.
- Make sure the parents understand the array of services available under Early Start.
- Fully explain IFSP services for which you are seeking permission or consent.
- Give the family reports, records, and copies of the IFSP.
- Explain the concept of natural environments to families. Help them understand that services are to be provided in the places in which their family needs support in order for their child or family to participate as fully as possible in those activities.
- Fully explain when, how, and why services would be considered and delivered outside the natural environment.

TIPS FOR SUCCESS

- Use a checklist, such as the Checklist for Explaining Early Start Procedural Safeguards to Parents (in the Resources section of this chapter), to ensure that your conversation with the family covers all aspects of procedural safeguards. The benefit of going through a checklist each time is that you can assure yourself that you have not missed any steps. Of course, the trick is not to have the conversation sound rote or rehearsed. This takes practice.
- Be prepared with multiple ways to explain each safeguard, examples to illustrate what they mean, and a variety of levels of depth of explanation to match the parents' need. The level of explanation should be driven by parent need or request. Understanding Procedural Safeguards: Examples of Explanations and Implications for Families (in the Resources section of this chapter) offers sample scripts to help you explain procedural safeguards to parents.
- Offer families a copy of Parents' Rights: An Early Start Guide for Families, translated in their language of choice if available. Discuss this resource at appropriate times during the evaluation, assessment, and IFSP development processes. Parents' Rights is included in the Resources section of Chapter 8 and is available for download from <https://www.dds.ca.gov/services/early-start/early-start-publications-resources-and-program-guidance/publications>
- Provide parents with a family-friendly tool such as Procedural Safeguards: Key Points About Your Family's Information and Decision-Making (in the Resources section of this chapter) to help them understand and advocate for their rights.
- Be repetitive when explaining procedural safeguards. Parents may need to hear and talk about their rights multiple times in order to fully understand them.
- Familiarize yourself with your agency's procedural safeguard forms and be prepared to explain them to families.
- Document parental consent and file copies of all procedural safeguard forms and written notices in the child's record. Encourage parents to do the same.
- Parents want the best for their child. If a family refuses or withdraws consent, it may be helpful to initiate a discussion about the reasons for their decision.

There might be questions that need to be answered, information that needs to be clarified, or issues that need to be addressed.

- In the child's record, document each time the record is accessed by the parent, whether the parent's request was verbal or written.
- Contact the child's welfare case worker to ensure that the educational rights of the parents have been limited or removed by the court or relinquished by the parent before assigning a surrogate parent.

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A Checklist for Explaining Early Start Procedural Safeguards to Parents

At Intake

Explain consent [52162],¹ including right to refuse or withdraw consent [52162(b)(2)]

Explain confidentiality of records [52160(c)]

- access rights [52164]
- copy fees [52167]
- right to request amendment to records [52168(b)]
- release of information [52169]
- personally identifiable information [52000(b)(46)]

Implement surrogate parent if applicable [52175]

Obtain written consent prior to evaluation and assessment [52162]

If Parent Refuses Evaluation and Assessment

Ensure that parent is aware of the nature of evaluation and assessment that would have been provided and that the child will not receive the evaluation and assessment [52162(c)]

Evaluation and Assessment

Explain and provide written initial notice [52160] and written prior notice [52161]

Explain voluntary identification of family concerns, priorities, and resources [52084(d)]

Explain nondiscriminatory procedures including native language/usual communication mode [52082(g)]

Explain interim IFSP if applicable and obtain consent [52107]

Introduce procedures for resolving individual child complaints [52170], including mediation [52173]

¹Numbers in brackets reference Title 17, California Code of Regulations, Chapter 2, Early Intervention Services

If Child Is Not Eligible

Explain procedures for resolving child complaints [52170] and mediation [52173]

Individualized Family Service Plan (IFSP) Development

Plan IFSP meeting: written notice [52102(h)], timelines [52102(a)], parent's convenience and native language [52102(g)]

Explain and provide written prior notice [52161]

Explain the right to decline services without jeopardizing other services [52162(b)(3)]

Obtain written consent required for initiation of services [52162]

If Parent Declines Service(s)

Ensure awareness of the nature of service(s) that would have been provided and that the child will not receive the service(s) [52162(c)]

Explain procedures for resolving individual child complaints [52170], including mediation [52173]

IFSP Implementation

Explain periodic and annual review [52102]

Explain changes in provision of services [52102] and required written notice [52161]

Obtain written consent for newly initiated services [52162]

Explain and provide annual notice [52160]

Transition: give prior notice, explain timelines, discuss placement options [34 CFR 303.209²]

²34 Code of Federal Regulations Part 303, Regulations for the Early Intervention Program for Infants and Toddlers with Disabilities (Part C) under the Individuals with Disabilities Education Act (IDEA).

Adapted from Hurth, J., and Goff, P. (2002). Assuring the family's role on the early intervention team. Chapel Hill: National Early Childhood Technical Assistance Center.

Understanding Procedural Safeguards: Examples of Explanations and Implications for Families

Rights and safeguards under Title 17, California Code of Regulations, Chapter 2, Early Intervention Services

The following are samples of language that might be used by an Early Start service coordinator to explain procedural safeguards and their implications to families.

General written notice (§52161)

The early intervention program must give you advance written information about any evaluations, services, or other actions affecting your child. Parents know their children best. The information you share with us will make sure that the evaluations and services are right for you. The “paper work” assures that you get all the details before any activity.

Use of parent’s language of choice (§§52161 and 52162)

It is your right to thoroughly understand all activities and written records about your child. If you prefer another language or way of communicating (explain relevant option, such as braille, sign language, etc.), we will get an interpreter (use your mode of communicating), if at all possible. The early intervention program wants you to understand so that you can be an informed team member and decision-maker.

Informed consent (§§52162 and 52169)

The early intervention program needs your permission to take any actions that affect your child. You will be asked to give your consent in writing before we evaluate or provide services. Be sure you completely understand the suggested activities. By being involved, you can help the early intervention program plan services that match your family’s needs and preferences. The early intervention program needs to explain what happens if you give your consent and if you do not give your consent.

Confidentiality and release of information (§52169)

The early intervention program values the information you and other service and health care providers have learned about your child. We will ask others for this information, but we need your written permission to do so. Just as the early

intervention program needs your permission to get your child's records from other providers, the records that the early intervention program will develop will not be shared with anyone outside the Early Start system unless you give your permission.

Accept or decline services without jeopardy (§52162)

With the other members of your child's early intervention team, you will consider which services can best help you accomplish the outcomes that you want for your child and family. You will be asked to give your consent for those services you want. You do not have to agree to all services recommended. You can say no to some services and still receive the services you do want. If you decide to try other services at a later date, you can give your consent then.

Access and examine records (§52164)

The early intervention record is your family's record. You can see anything in the early intervention program's records about your child and family. If you do not understand the way records are written, the information in the child's record will be explained to you in a way you understand. You are a team member and we want you to have the same information as other team members.

Adapted from Hurth, J., & Goff, P. (2002). Assuring the family's role on the early intervention team. Chapel Hill: National Early Childhood Technical Assistance Center.

Procedural Safeguards: Key Points About Your Family's Information and Decision-Making

Confidentiality: Protecting Your Family's Personal Information

- Any information that would allow someone to personally identify your family is protected.
- You control who sees or hears information about your child and family.
- You control the amount and type of information you choose to share.
- Before sharing the name, address, phone number, social security number, personal characteristics, or other information that would make it possible to identify your child, you, or other family members, Early Start professionals must ask you for written permission, called consent.
 - Note: In California, referral information is sent to the local educational agency before your child turns 3 years old and does not require parental consent. The information provided includes the child's name, date of birth, the parents' names, mailing address, and phone number. Any additional information can only be sent with your consent.
- If you aren't sure, ask why confidential information is being collected.

Consent: Participating in Decisions About Your Child and Family

- You are a partner in all decisions made about services for your child and family, especially those that involve a change in eligibility or services. Whenever you are being asked to agree to a decision made about services for your child and family, the Early Start program must ask for your consent.
- You have the right to informed consent, meaning that you understand what you are being asked to agree to.
 - Ask questions to make sure you understand and agree with every activity in the process.
 - Ask the program to offer information in your language of choice.
- Your agreement is voluntary. At any point you can refuse to accept or decline any activity, request, or service and to change your mind.

- If you refuse to accept or decline an activity, request, or service, your child and family will still receive the activities and services to which you do agree.

Notice: Knowing About Important Meetings for Your Child and Family

- Expect a written notice, in your language of choice, before any meeting in which a decision is to be made around eligibility or services for your child or family.
- You should receive the written notice early enough to plan to attend the meeting and invite others if needed or wanted.
 - Only agree to accept a meeting with short written notice if you are truly comfortable doing so.
 - Invite anyone you think needs to be there to support the development of the IFSP. This may include friends, advocates, other service providers, and childcare providers.
- If your child is not eligible for services, you should receive that information in writing and may ask for a full explanation of the evaluation.

Access: Knowing What Is in Your Child's File

- You may see your child's Early Start file at any time. If you request to see your child's file, the regional center or local educational agency must let you do that within five working days of your request. Your request may be verbal or written. If you make a verbal request, make a note of when you made the request, and to whom, for your own records.
- Viewing your child's file is free. If you request copies of records in your child's file, there may be a fee charged.
- If there is anything in your child's file that you think is wrong or that violates the privacy of your child and family, you may ask that it be removed or changed. If it is not removed or changed, you may add your own statement to your child's file.
- If anyone (other than you, as the parents, and authorized representatives of the Early Start agency) has reviewed your child's file, there must be a record of their name, the date the file was accessed, and the reason the file was accessed.

ENDNOTES

¹The Quality Practices section was adapted from the following articles:

Workgroup on Principles and Practices in Natural Environments. (2008). Agreed upon practices for providing early intervention services in natural environments. Retrieved from http://ectacenter.org/~pdfs/topics/families/AgreedUponPractices_FinalDraft2_01_08.pdf

Kemp, P., Turnbull, A., & Turnbull, R. (2014). Promises to families policy concepts: Rights and roles guiding services for families of infants and toddlers with disabilities. Retrieved from http://ectacenter.org/~pdfs/calls/2017/PromisesToFamilies_2015.pdf

Hurth, J., & Goff, P. (2002). Assuring the family's role on the early intervention team: Explaining rights and safeguards. Retrieved from <https://ectacenter.org/~pdfs/pubs/assuring.pdf>

PUBLISHING INFORMATION

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For information about California Early Start, contact DDS at 800.515.BABY, visit www.dds.ca.gov/services/early-start, or email earlystart@dds.ca.gov.

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