Assuring the Family’s Role on the Early Intervention Team

Explaining Rights and Safeguards

Joicey Hurth & Paula Goff
Frank Porter Graham Child Development Institute
The University of North Carolina at Chapel Hill

June 2002, 2nd Edition

The National Early Childhood Technical Assistance Center
The National Early Childhood Technical Assistance Center (NECTAC) is a program of the Frank Porter Graham Child Development Institute of The University of North Carolina at Chapel Hill with the National Association of State Directors of Special Education (NASDSE) and Parent Advocacy Coalition for Educational Rights (PACER Center)

June 2002, second edition

This resource is produced and distributed by the National Early Childhood Technical Assistance Center (NECTAC), pursuant to contract ED-01-CO-0112 and no-cost extension of cooperative agreement H024A60001-96 from the Office of Special Education Programs, U.S. Department of Education (ED). Contractors undertaking projects under government sponsorship are encouraged to express their judgment in professional and technical matters. Opinions expressed do not necessarily represent the Department of Education’s position or policy.

Additional copies of this document are available at cost from NECTAC. A complete list of NECTAC resources is available at our Web site or upon request.

For more information about NECTAC, please contact us at:
137 E Franklin Street, Suite 500
Chapel Hill, NC 27514-3628

919-962-2001 ★ phone
877-574-3194 ★ TDD
919-966-7463 ★ fax

nectac@unc.edu ★ www.nectac.org

Principal Investigator: Pascal Trohanis
Contracting Officer’s Representative at OSEP: Peggy Cvach
Contract Specialist at U.S. ED: Dorothy Hunter
Author: Joicy L. Hurth
Publications Coordinator: Caroline Armijo
Introduction

The procedural safeguards required by The Infants and Toddlers with Disabilities Program (Part C) of the Individuals with Disabilities Education Act (IDEA) are intended to protect the interests of families with infants and toddlers with special needs and of the early intervention system. Procedural safeguards are the checks and balances of the system, not a piece separate from the system. For families, rights and safeguards help ensure that an Individualized Family Service Plan (IFSP) is developed that addresses their priorities and concerns. For the early intervention system, rights and safeguards assure quality and equity. For families and for the system, procedural safeguards provide the protection of an impartial system for complaint resolution. Early intervention system personnel are legally obligated to explain procedural safeguards to families and to support an active adherence to and understanding of these safeguards throughout the early intervention system.

In order for families to be fully informed of their rights and safeguards, they also must understand the early intervention system and their role as partners and decision-makers in the early intervention process. They should be advised that the intent of Part C of IDEA is to enhance families’ abilities to meet the special needs of their infants and toddlers by strengthening their authority and encouraging their participation in meeting those needs.

This paper is a synthesis of practices and ideas for explaining procedural safeguards to families, which assure that families are fully informed in ways that support their role in the early intervention process. The authors solicited information about practices and ideas for explaining procedural safeguards to families from early childhood projects funded by the Office of Special Education Programs of the U.S. Department of Education and from the state lead agencies for Part C. The paper includes a step-by-step model of explaining procedural safeguards that parallels the early intervention process. The authors intend to explore the implications of procedural safeguards for families, but not to analyze the Part C safeguards themselves. The paper has been developed for state Part C leaders, service providers, families, family advocates, and especially for those people who are involved in explaining procedural safeguards to families.

2002 Edition

The 1997 Amendments to the IDEA required an update to the original 1996 edition of this monograph. The most substantive change to the rights and safeguards discussed in this monograph was the requirement that states ensure that mediation services are available as part of complaint resolution procedures. The revised 2002 edition incorporates the new regulation (34 C.F.R. 303.419). At this time many excellent materials have been developed to explain procedural safe-
guards in family-friendly ways. A new collection of materials was not undertaken for the current revision. However, the original examples cited are still useful to illustrate principles of developing family-friendly materials, even if the cited materials are no longer available. The reader is encouraged to request the most current materials for families from their state’s lead agency for Part C. A complete contact list for all states lead agencies is available on the NECTAC web site at http://www.nectac.org/.

Background and Issues

The primary safeguard provided for in Part C is the clear acknowledgment of the family’s role as a primary decision-maker in developing an IFSP. Part C regulations strengthen and clarify a family’s right to accept or reject any service without jeopardizing other services that they want (see 34 C.F.R. §303.405). The family-centered spirit of early intervention affords an opportunity to develop new strategies for supporting families in informed partnerships with the system and to change practice that too often has been perfunctory, adversarial, or culturally insensitive.

For example, a common method of informing parents of the safeguards guaranteed them is to provide them with written materials about these safeguards during intake or entry into an early intervention program. At that time, providers may review the materials with families who then are asked to sign all of the informed consent forms and releases. Often, these documents are nothing more than direct citations of the law. Sometimes, the safeguards are listed in a “you have the right to” format, reminiscent of being “Mirandized” or being read your rights. Procedures such as these assume that all families can read English, can interpret legal rights, and feel free to assert themselves and ask questions.

Such procedures are likely to produce unfortunate consequences. Many families and service providers come to view procedural safeguards as administrative paperwork that only becomes important when a problem arises. This attitude is a disservice to families and providers because it belittles a hard-won legacy of respect for and protection of families’ rights and safeguards that strengthen service systems. Worse, families can be overwhelmed by the legal jargon, by the adversarial connotations, and by a lack of understanding of why these rights are necessary. When families are asked to sign a stack of consent forms, the legal aspects of the relationship with providers are emphasized.

Meeting legal requirements can be an opportunity for service providers to begin teaching families about safeguards while conveying their respect for the role of families in the early intervention system. Unfortunately, this opportunity frequently is missed, often because service coordinators and/or service providers are not fully trained in procedural safeguards, have a limited understanding of them, and find them difficult to explain when questioned. Although the method of overwhelming families with paperwork during their first contact with the system may comply with the letter of the law, it does not assure that families are fully informed. Families are not fully informed until they understand the early intervention system and their role in the system. Rights and safeguards are an integral part of this basic information.

Understanding Procedural Safeguards: Implications for Families

A simple listing of rights and safeguards does not adequately convey the meaning of these protections.

Each right and safeguard has implications for a family’s experience with the early intervention system. Further, because Part C is family-oriented legislation, the rights and safeguards convey the law’s central principles of respect for families’ privacy, diversity, and role as informed members of the early intervention team.

Table 1, Understanding Procedural Safeguards: Examples of Explanations and Implications for Families (see page 4), lists some of the central rights and safeguards under Part C that must be addressed during the process of planning and providing services. The bold headings
in Table 1 are the section headings from the Part C regulations (34 C.F.R. §303), followed by the section citation in parentheses. The text below each heading is not the actual regulatory language but rather an example of how a service provider could explain to families the safeguard and its implications. The regulatory text pertaining to procedural safeguards under Part C of IDEA (34 C.F.R. §§303.400–.460) is reproduced in the Appendix.

**Assuring That Families Are Fully Informed Team Members: A Step-by-Step Model**

Assuring that families are fully informed of their rights and safeguards requires ongoing explanations in the context of the early intervention process. It would be impossible to fully understand and appreciate the safeguards before having had any experience with the procedures. Figure 1, *Explaining Part C Procedural Safeguards to Families: A Step-by-Step Model*, outlines the information that families need to understand at each step in the process, from referral through IFSP development and service implementation. Each box in Figure 1 represents a major step in the development of an IFSP. Citation numbers in parentheses at the end of each sentence refer to the relevant sections of Part C regulations. Safeguards are intentionally repeated at different steps (boxes) because of the numerous times within the process that a safeguard may apply. Italicized words indicate a recommended practice, not one that is required by legislation. Figure 1 is a generic model and should be adapted to illustrate specific procedures used by an early intervention program or agency.

The model suggests that families need information to support their role as team members throughout the IFSP process. At each step of the IFSP process, important decisions must be made. Only to the extent that families understand their options can they fully exercise their decision-making authority as part of the early intervention team.

During early contacts, families should be invited to participate as key members of the early intervention team and should be oriented to the early intervention system and services. This orientation should include an introduction to rights and safeguards. The introduction can be supplemented with a variety of easily accessible materials about the early intervention system, as well as about rights and safeguards, to which families can refer over time (see the section “Principles and Practices from States and Projects for Creating and Using Family-Friendly Materials” below). The Step-by-Step Model does not suggest that all rights and safeguards be presented in detail at first contact unless a family requests such information. Rather, an explanation of each right and safeguard is provided in the context of each procedure to which it relates.

Explaining the safeguards and their implications clarifies how the early intervention system operates and exemplifies the family’s role in the system. Each step of planning with a child’s family provides an opportunity to discuss the relevant rights and safeguards and their meanings or implications. For example, before evaluation it is important to explain prior written notice. It is also important to operationalize the meaning of this safeguard by statements such as:

> You will receive a letter explaining the evaluation procedures we discussed and why we are doing them. It will also remind you of the time and location on which we agreed. This letter is an example of prior written notice, a legal requirement, which assures that the early intervention program explains to parents what it plans to do. You will receive other written notices like this, before we initiate or change any services for your child.

As suggested by the Step-by-Step Model (see Figure 1, page 6), other safeguards that should be explained before evaluation include consent, [native language or preferred mode of communication], and confidentiality of records. The implications of these procedural safeguards in the context of evaluation include the family’s right and need to fully understand suggested evaluation procedures so that their consent is truly informed. Further, these safeguards acknowledge that families are from diverse backgrounds and that the early intervention program will accommodate their commu-
Table 1
Understanding Procedural Safeguards: Examples of Explanations and Implications for Families

Rights and safeguards under 34 C.F.R. § §303. 400–460.
Regulations for the Early Intervention Program for Infants and Toddlers with Disabilities, Part C of IDEA

Written prior notice (§.403)
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 native language or preferred mode of communication (§§.401 and .403)
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.

Parent consent (§.404)
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 preferences and needs. 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 (§§.401-.404)
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 unless you give your permission.

Examine records (§.402)
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.

Accept or decline services without jeopardy (§.405)
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 that you want. You do not have to agree to all services recommended. You can say no to some services and still get the services that you do want. If you decide to try other services at a later date, you can give your consent then.

Mediation (§.419)
If you and the early intervention team do not agree on plans or services, or if you have other complaints about your experience with the program, there are procedures for resolving your concerns quickly. When informal ways of sharing your concerns don’t work, you may submit a written request for a due process hearing. Mediation will be offered as a voluntary first step. A trained, impartial mediator will facilitate problem-solving between you and the early intervention program. You may be able to reach an agreement that satisfies you both. If not, you can go ahead with a due process hearing to resolve your complaint. Mediation will not slow down the hearing process. Some locations offer mediation before a formal complaint is filed.

Due process procedures (§.420)
A due process hearing is a formal procedure that begins with a written request for a due process hearing. The hearing will assure that a knowledgeable and impartial person, from outside the program, hears your complaint and decides how to best resolve it. The early intervention program recognizes your right to make decisions about your child and will take your concerns seriously. You are given a copy of regulations that describe all these rights and procedures in detail, because it is important that you understand. If you have questions, call _____________________________.

Bold type: Section headings from regulations.
Narrative: Sample of language that might be used by an early intervention system to explain implications of regulations to families.
communication preferences. One implication of the confidentiality safeguard is that, with the family’s permission, the program will coordinate records with other providers on behalf of the family. In addition, families are reassured that information they share will be treated confidentially, unless they choose to release it.

The above examples illustrate rights and safeguards that should be explained in early contacts with families, prior to evaluation and assessment. These same safeguards and how they apply to other procedures should be reiterated at subsequent steps of the IFSP process, as suggested by Figure 1. Such explanations of procedures contain powerful messages about early intervention’s operative principles, such as respect for families’ privacy and diversity and value as informed partners on the early intervention team.

Explanations of rights and safeguards should be a part of the service provider’s ongoing conversations with families. Rights and safeguards are an integral part of the basic information about how the system works. Reiterating rights and safeguards and their implications for families at each relevant step is a way to support a family’s evolving understanding.

As equal team members, families need the same information as the other team members. When all team members are informed and follow basic procedural safeguards, the process goes more smoothly, the team can make more appropriate plans and decisions, and the team can work smarter, not harder.

**Explaining Procedures for Complaint Resolution**

Although many rights and safeguards can be explained when they occur in the early intervention process, some need to be explained from the beginning in case a family may need them. Due process procedures for resolving complaints are the most important example. Within the parameters of any relationship, disagreements arise; relationships between family members and service providers are no different. Disagreements are part of the process of interaction and provide opportunities for exploring options and solutions. When family members and service providers disagree about eligibility or IFSP issues, an opportunity arises for an open discussion of interests, options and alternatives. There is no single correct method of early intervention. What is available is a wide variety of options, ideas, and solutions that can be tailored to fit the needs and values of each individual child and family. Service providers and early intervention programs should have many informal methods of hearing from families that prevent or resolve concerns quickly (see below). However, family members must also be informed about their right to formal complaint resolution procedures.

Under Part C regulations, states choose either to develop due process procedures to meet the requirements of the Part C regulations (34 C.F.R. §303.419 and §§303.420–.425), or to adopt Part B child complaint process (34 C.F.R. §§300.506–.512, and meet the requirements of §303.425).

For families, an important difference between these regulations is that Part C calls for a shorter time period for resolving a complaint—30 days as opposed to 45 days under Part B. While most states have developed Part C procedures, some states, particularly those in which the education department is the Part C lead agency, have adopted the Part B procedures. Recognizing that infants’ needs change rapidly, several of these states encourage service providers and hearing officers to use the 30-day limit, instead of the 45-day limit under Part B, for complaint resolution. States are also required to provide parents an appropriate means of filing a request for a due process hearing. An impartial, knowledgeable hearing officer listens to viewpoints about the dispute, examines information, seeks a timely resolution and provides a record of the hearing, including a written decision. Parents have many rights during these procedures, including having an attorney or other knowledgeable persons accompany them, presenting evidence, cross-examining and compelling witnesses, and having evidence disclosed to them before the proceedings. They may obtain a verbatim transcription of the proceedings and writ-
Explaining Part C Procedural Safeguards to Families: A Step-by-Step Model

Text in italics indicates practices that are recommended but not required by legislation.

Referral (.321(d))
- Distribute materials on availability of EI services (.320)
- Explain referral information (name, address) will be shared (FERPA)

Parent Refuses Evaluations
- Explain right to decline services (.405)
- Assure awareness of consequences of refusal (.404)
- Explain notice of override (.404, Note 2)

Intake Procedures — First Contacts
- Orient to EI services; overall procedures; rights and safeguards; parent’s role; IFSPs
- Explain available advocacy and parent support programs
- Explain prior notice (use of native language or usual communication mode) (.403)
- Explain consent (.404)

Parent Refuses Evaluations
- Explain procedures for resolving child complaints (.420) and mediation (.419)
- Refer to other community resources as appropriate

Evaluation and Assessment
- Explain eligibility
- Explain evaluation procedures and instruments, timelines, and parent’s role in process
- Provide written prior notice (action, reasons, available safeguards) (.403)
- Provide written consent (for evaluation) (.403-.404)
- Explain voluntary identification of family concerns, priorities, and resources (.322(d))

Ineligible
- Explain procedures for resolving child complaints (.420) and mediation (.419)
- Refer to other community resources as appropriate

IFSP: Decline All Services
- Explain procedures for resolving individual child complaints (.420) including mediation (.419)
- Explain how to access services if desired in the future

IFSP (.340-.346)
- Plan IFSP meeting: written notice, timelines, (.342(e)) participants’ convenience, accessibility, native without language (.342(d))
- Explain array of EI services and entitlements

IFSP Acceptance and Implementation of IFSP
- Explain periodic review, annual evaluation (.342)
- Explain changes in provision of services, required notice, and possible consent for newly initiated services (.403)
- Transitions (.148 and .344(h)): prior notice, timelines, placement options, consent for record transfer (.401—.404)

IFSP Acceptance and Implementation of IFSP
- Explain termination of services: prior notice (.403); child complaint procedures (.420); help families transition out of special services, if appropriate

1 Numbers in parentheses reference 34 CFR Part 303, Regulations for the Early Intervention Program for Infants and Toddlers with Disabilities (Part C) under the Individuals with Disabilities Education Act (IDEA)

Hurth and Goff © NECTAC 2002
ten findings of fact and decisions (Part C §303.422 or Part B §300.509).

Because of the the 1997 reauthorization of IDEA, a regulation (§303.419) was added requiring states to offer mediation when a written request for a due process hearing is filed. Mediation services are provided at the state’s expense and are voluntary for families. An impartial, trained mediator will try to facilitate an agreement between the family and the Early Intervention program or provider. Mediators do not make decisions; they facilitate problem-solving. Both parties must be satisfied with the agreement they reach or the dispute will continue to the due process hearing. Mediation may not prolong the time limit for due process procedures. Many see mediation as an opportunity for parents, service providers, and an impartial mediator to creatively generate options for resolution of concerns, and to avoid more formal procedures that tend to be adversarial and costly for families and for early intervention systems. In fact, many states are making mediation services available to families before they file a formal request for a hearing.

In order to develop truly family-centered practices, early intervention programs, the community-based system, and the state lead agency need to establish multiple avenues to encourage family evaluation and feedback about their experiences in early intervention. Adapting overall program practice to meet families’ expressed needs and preferences can create a service culture that is responsive to families and may prevent formal complaints. Different families will have different levels of comfort with and different preferred means of voicing concerns and offering evaluations.

Establishing a variety of opportunities for input could include such strategies as:

- open-door policies that invite parents to talk to administrators;
- ongoing program evaluations, using multiple methods of information gathering (e.g., written evaluations, interviews, focus groups, exit interviews, IFSP analyses, reviews of progress towards outcomes);
- a policy that acknowledges the importance of a good match between a service provider and each family and that allows for parent choice in assignments;
- a suggestion box or other avenues for submitting comments anonymously;
- parent-to-parent support and/or parent group opportunities;
- parent advisory board members;
- ongoing availability of interpreter or translator services;
- a designated contact person in the state-level Part C system for parents to call when they are concerned about services or procedures; and
- mediation services offered before a formal complaint is filed.

Principles and Practices from States and Projects for Creating and Using Family-Friendly Materials

As a part of a family-centered process of explaining rights and safeguards, service providers must recognize that each family—indeed, each family member—has a different approach to accessing and using information. To accommodate these unique approaches, providers must individualize the timing and methods of sharing information to match each family member’s interests, needs, and preferences. The use of multiple methods of sharing information and the use of a variety of family-friendly materials are key approaches to respecting each family member’s preferred learning mode. Because families have different levels of experience and comfort with formal early intervention service systems, a diverse group of experienced parents and community representatives should be informed about and available to explain services and safeguards.

A review of materials and information submitted by states and projects to the authors yielded the following principles and examples of creating and using family-friendly materials.

Many see mediation as an opportunity for parents, service providers, and an impartial mediator to creatively generate options for resolution of concerns, and to avoid more formal procedures that tend to be adversarial and costly for families and for early intervention systems.
★ Use family-friendly language and a clearly stated philosophy of family-centered services.

When procedural safeguards are fully endorsed as a vital component of the early intervention system, the philosophy of family-centered services is clearly stated throughout the variety of materials used to explain family rights and safeguards.

The language that is used should be free of professional jargon and “legalese” (direct citations from the law without explanation). The reading level of the materials should be similar to that of popular newspapers and magazines (about the fourth- to fifth-grade level). However, care must be taken to assure that while the reading level is simple, the content is not. Simple sentences (as opposed to compound, complex sentences), short, common words (e.g., “use” instead of “utilize”), and active verb tenses (e.g., “take” rather than “could be taken”) convey important information without talking down to families.

The language of materials can also carry messages about who is invited to use the information and, perhaps unintentionally, who is excluded. Today’s families are not always comprised of mothers and fathers or parents and their children. Materials portraying this concept of family may exclude foster parents, grandparents, unmarried mates, or other people significant to a child’s life. Except in instances when the legal requirements specifically limit a right or safeguard to parents or legal guardians, the language of materials should use inclusive terms like “family,” “friends,” “people who are important to you and your child,” and “caretakers.”

The following excerpts from print materials exemplify the language and philosophy of family-friendly materials:

Parents are decision makers on the team. . . . You have many rights as the parent of a child receiving early intervention services. These rights are called procedural safeguards. All early intervention service providers must have written procedural safeguards. Because your rights are so important, your service coordinator must review them with you before the program of services begins and at least once a year thereafter. Please be sure you are given written information about your rights (Garland, 1992, p. 31).

When I need early intervention services, the Department of Health has 45 days to complete my evaluation unless I get sick or my family needs more time. . . . We can have other members of our family, a friend, an advocate (supporter), or even an attorney present during the IFSP meeting if we’d like. . . . Should we disagree with any of the recommendations being made or think we are not receiving the services we need, we have a right to voice our concerns (Hawai’i Department of Health, n.d., pp. 2–5).

★ Present procedural safeguards in the context of information about early intervention services and the IFSP process.

The same rationale for explaining rights and safeguards in the context of the early intervention process applies to the content of print, video, and other materials. Information on rights and safeguards should be presented with information on the early intervention system and services, the IFSP process, and the family’s role on the early intervention team. The following examples illustrate different approaches to embedding rights and safeguards in information about the Part C program.

Lengthy and complex information can be broken apart conceptually and presented in brief, attractive pamphlets that can be discussed with families at the appropriate step of the early intervention process. Project Vision at the University of Idaho has created Parents as Partners in Early Education (Project Vision, 1992b), a series of 16 booklets, each explaining an aspect of early intervention services under Part C or preschool services under Section 619 of Part B. Titles in the series provide overviews to such topics as protecting family rights or procedural safeguards, IFSPs/IEPs, early intervention or preschool services, IDEA, service coordination, child assessment, gathering family information,
and transition issues. Each booklet is quickly identified as one of a series by the consistent use of title, format, and graphics. The language is family-friendly and the text is concise and readable while conveying the necessary information.

Project Vision (1992a) also produced the Parent Satisfaction Ratings series in a similar brief format which asks families to evaluate key aspects of information received and their experience relevant to the steps of the process outlined in the Parents as Partners series. For example, Helping Families Learn about Family Rights seeks family members’ thoughts and feelings about questions such as:

“I believe the people helping my child really tried hard to explain my rights to me”;

“I know that I can read my child’s file whenever I want”; and

“I know that if I do not like the services my child is getting I can request a meeting to talk about my needs” (p. 3).

Another approach is to produce a family manual or handbook that provides an overview to the early intervention program, including rights and safeguards, and refers to other materials that address various topics in more detail. The manual is useful for orientation and the supplemental pieces can be used throughout the process as families need and want more detail. For example, the Maryland Infants and Toddlers Program developed Dreams & Challenges: A Family’s Guide to the Maryland Infants & Toddlers Program (1992a), and three brochures: Parents’ Rights in the Early Intervention System (1992d); Mediation in the Early Intervention System (1992c); and Impartial Procedures for Resolving Individual Child Complaints (1992b).

★ Use a variety of media produced in multiple languages to accommodate individual needs and preferences for receiving and understanding information.

Although Part C requires that families receive written information on their rights and safeguards, investment in multiple media presentations of information greatly expands options on how, when, where, and who receives information on rights and services. They also accommodate different learning styles and preferences. Print materials, even with multiple translations, are not accessible by everyone. Some cultures have a tradition of sharing information orally. Many people have difficulty reading or learn better and more quickly through listening. And most people better understand information when it is presented in more than one way.

When face-to-face contact may not be convenient or appropriate, audiotapes and audio-video cassettes can be loaned to parents, extended family members, and concerned others. They can be played in homes and in pediatricians’ offices, placed in libraries, and used in training, public awareness, and child find activities. Alaska’s Part C program discovered that almost all the remote frontier villages had at least one video cassette player and that community viewing of informational tapes was a popular winter pastime. The Alaska program is developing videos in a number of native dialects and languages that can be maintained within each rural village.

The Colorado Department of Education has produced videos on procedural safeguards, the IFSP, and service coordination. Staying in Charge: Information for Families and Service Providers about Family Rights (M. Herlinger, 1993) presents comprehensive information about procedural safeguards in the context of family stories about their children and their involvement with the early intervention process. The presentation is family-friendly and safeguards are explained through the families’ experiences.

When developing and translating materials, it is important to assure accurate and understandable translations. Materials should be reviewed by several members of the community for which the materials are intended. Special care should be taken with legal concepts that may not have direct translations into another language. English words may need to be used and fully defined and explained. Also, print and video materials should include visual depictions of people of diverse cultures and people with disabilities.
Assure accessibility of information by enhancing materials’ appeal, availability in multiple community locations, readability, and inclusion of interpretive supports.

Appeal and attractiveness enhances the use of the materials by families and service providers. Pictures and graphics break up blocks of text. Several parent handbooks (see for example, Fortune, Dietrich, Blough, & Hartman, 1993; Maryland Infants and Toddlers Program, 1992a; Texas Early Childhood Intervention Program, 1991) have graphics such as headings, boxes, and pictures, placed between small amounts of text. This breaks up the narrative and allows readers to view small pieces of information at a time. Some parent handbooks are written in an easy-to-read, question-and-answer format with very little professional jargon or legalese. The questions also are typical of those that parents ask and the answers provide simple yet thorough explanations of the issues. For example,

What information will I be asked to share about my family?

You can share whatever family information you choose. It’s up to you. Providers will give you a chance to discuss family needs. They should only ask for information about your family which is important to the evaluation of your child (Gilmer, 1992, p. 9).

One handbook submitted to the authors included tips for families interspersed throughout the handbook. Parents assisted in writing the tips, which gave a first-hand perspective. Some handbooks include glossaries of terms and acronyms to help readers understand the early intervention system’s language.

*Early On*, the parents’ handbook produced by Michigan’s Part C system, advises families: “If anyone uses any initials you do not understand, ask what they mean” (Fortune et al., 1993, p. 26).

Another approach is to develop a handbook that is designed to be a personal record of the child and family as well as a record-keeping tool for the early intervention system. The book may be used more frequently by the family and service providers if it is introduced to the family at the beginning of their relationship with the system, and if the format encourages the family to personalize the handbook with pictures and anecdotes and contains space for copies of early intervention records, medical records, IFSPs, and other notes. When the book is used more, more opportunities occur to read information about the system of early intervention services.

Any format used to provide information to parents needs to use language that supports partnership. For example, language such as “with your direction and agreement,” “you know your child like no one else,” and “you are part of a team” indicates the expectation that families and service providers work together. Terms like “due process” connote an adversarial relationship, whereas describing the “procedures to resolve a complaint” connotes negotiation and communication. Some pamphlets have been developed with wording such as “impartial ways to resolve concerns” or “ways we can problem-solve.”

A few materials described mediation in a manner that recognizes that disagreements occur and are part of the process. “Sometimes families of infants and toddlers with special needs disagree with their service providers. Most often these situations are worked out but when that honest effort falls short, families and service providers can find agreement through mediation. With the help of a neutral third party, cooperation, agreement and solutions can become reality” (Hawai‘i Department of Health, 1991, p. 1).

When information is provided by many methods and in many formats, the information is accessible to more families. The law requires that families receive information in the families’ preferred mode of communication. Therefore, early intervention systems need to develop materials and procedures that are available in a variety of languages and formats. Audio and video products make information available to nonreaders and others who prefer these formats.
Another method being explored is to train key community leaders in the early intervention system so that they can be a resource for families. In keeping with the Part C requirement to reach traditionally underserved families, informing and involving leaders of their communities can be an effective strategy. The use of community people as interpreters to provide information to families about the system and procedural safeguards also is being piloted by some states and projects. This appears especially helpful for families with a tradition of communicating orally. Some states are supporting local programs to recruit and train a cadre of people from diverse communities and languages to serve as service coordinators on a consulting or fee-for-service basis. The Navajo Nation developed an interim service coordination program, called *Growing in Beauty*, to help Navajo families access services from the three state systems which overlap the Nation’s boundaries and have responsibilities for providing early intervention services.

Experienced family members, who are well informed about the early intervention system, are being connected with families who are new to the system. Parents are being hired and trained as service coordinators, trainers, guides, and interpreters through the IFSP process. Some states have funded parent programs to provide these services (for example, Community Resource Parents in Vermont, Project LINC in Colorado, Parents as Partners in Early Intervention in Florida, and New Visions in Maryland). In other programs, parents and other community people volunteer to provide support and answer questions for the new family as they go through each step of the process.

Access to information also is improved by the use of several outlets for dissemination. Although state and local agency offices frequently are used as dissemination points, other outlets can include local physician offices, grocery stores, public libraries, churches, public health clinics, laundromats, and community programs. Many video rental stores stock public service tapes that are loaned free of charge. Public service announcements can be played on radio and television, and included in community newspapers.

**Conclusions**

Part C provides the opportunity to enhance relationships between families and service providers. Early intervention can prepare families for a lifetime of productive interaction with service systems. For this reason, investing the time and resources to thoroughly explain rights and procedural safeguards is an important service for all involved. Assuring families a role as partners and decision-makers in the early intervention system is an evolutionary process. Technical support and training is necessary to facilitate program level change to truly family-centered practice.

The Part C system is enhanced when a person or persons with expertise in procedural safeguards is (are) available for consultation with families and service providers. It is probably not feasible for every local service program to have someone on staff with specialized knowledge about all pertinent state and federal legislation and judicial decisions. Some states have designated a staff person whose responsibilities include being available to discuss questions and concerns from families and service providers. In one state’s experience, this designated staff person has been able to resolve most concerns. In fact, most concerns were a result of inadequate understanding of the rights, safeguards, and policies of the system (L. Bluth, personal communication, 1994).

The interagency approach to implementing infant and toddler services means that many service providers from multiple agencies will need to be trained in Part C procedural safeguards. These rights and safeguards may be different than current policy and experience of non-education agencies.

As states are developing training and technical assistance activities, care should be taken to
involve many relevant stakeholders (such as families, multiple agency providers, advocates, parent groups, and community leaders) as collaborative planners and participants in training. The benefits of multiple perspectives in discussions include learning together, developing true partnerships, and understanding one another’s experience and point of view.

Family-friendly, culturally appropriate approaches for explaining procedural safeguards need to be an integral part of program practice. Because family-centered early intervention services are interagency, community-based efforts, service providers from a variety of disciplines and agencies, family members, and other community members will need to become comfortable with a working knowledge of procedural safeguards which can be applied in daily experience in the early intervention process.

References


Hawai’i Department of Health. (n.d.). Dear family, on behalf of infants and toddlers with special needs [Brochure]. Honolulu: Zero-to-Three Hawai’i Project.


Citation

Please cite as


This document appears at http://www.nectac.org/pubs/pdfs/assuring.pdf and updates to the data herein will be announced at http://www.nectac.org/pubs/.