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ABSTRACT

This booklet for parents of young children with disabilities describes Colorado's Individualized Family Service Plan (IFSP) process. It provides information on IFSP guidelines, relates family stories and reflections for families and providers, and describes the values that drive the IFSP process in Colorado. Information is provided on characteristics of successful IFSP teams, relationships between providers and families, components of the IFSP, basic rights of parents of children with disabilities, and procedural safeguards. A glossary of relevant terms is provided. (CR)

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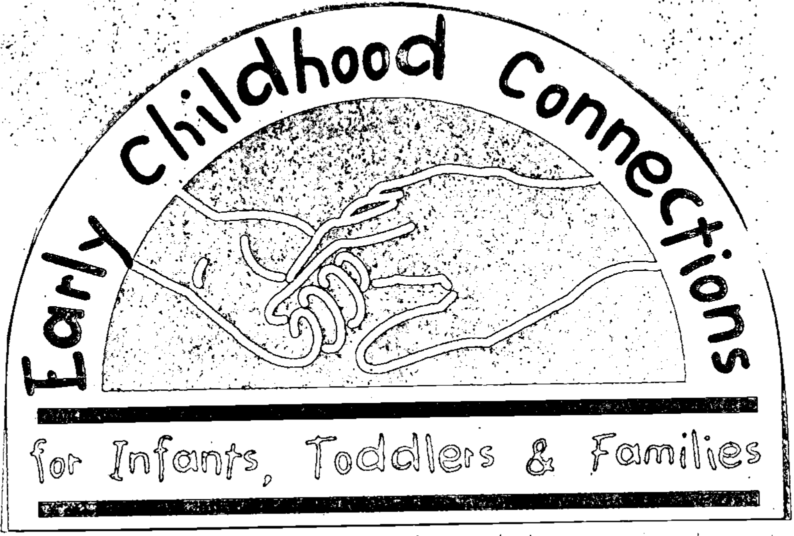
Jerri Miller and Sandy Petersen



Colorado Guidelines for the IFSP Process

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Colorado Guidelines for the IFSP Process

Written by:
Jerri Miller and Sandy Petersen

Developed by PEAK Parent Center, Inc. under a grant from the Colorado Department of Education cde

Early Childhood Connections
for Infants, Toddlers & Families

Early Childhood Connections, Colorado's infant/toddler initiative for Part C of the Individuals with Disabilities Education Act (IDEA)

For more information about Early Childhood Connections in Colorado call:

1-888-777-4041

Introduction

The Individualized Family Service Plan (IFSP) Process is a dynamic and exciting process that creates opportunities for enhancing the quality of life for infants and toddlers with disabilities and their families.

Disability is no longer seen as a negative force in a person's life. Each individual child and family member has gifts and strengths to contribute to their family and their community.

The IFSP is a planning process that provides an opportunity to build on these strengths and gifts by developing individualized supports and services that assure all babies in Colorado can reach their fullest potential.

This document is intended to guide families, providers and others through the IFSP process. Each section shares guidelines, family stories, reflections for families and providers and the values that drive the process in Colorado.

These guidelines underscore the value and spirit that are inherent throughout the Individuals with Disabilities Education Act (IDEA): families control their own destiny and the destiny of their children. Early Childhood Connections providers support them on the journey.

The Colorado Interagency Coordinating Council (CICC) sends these guidelines to families and providers in Colorado along with this challenge:

Use these guidelines to build Colorado communities where each child truly belongs and where all children have support to reach their fullest potential.

Possibilities

Creative, flexible, and collaborative approaches to services allow for individual child, family, and community differences.

Communities are enhanced by recognizing and honoring the diversity among all people.

The IFSP process serves many purposes. Perhaps the most significant is that it allows teams to view supports and services as the vehicle for infants, toddlers and families to create unlimited possibilities for enhancing development through meaningful participation in their communities.

The IFSP Team/Process begins by:

- Recognizing that each family is unique and individual with strengths and interests that can and should be built upon.

- Learning what each family enjoys doing, how family members spend their time and then creating supports and services that enhance those experiences.

- Listening while family members share their priorities and concerns and then designing supports and services that are unique and individual for that family.

Using family focused planning to blend formal and informal supports is the key to designing supports and services that reflect each family's individual culture. This is accomplished by:

- Considering a variety of strategies and activities for achieving each outcome including those which are not paid for with Part C funds.
- Utilizing regular family and child interactions to promote the child's development.
- Facilitating connections between families and natural community activities.
- Exploring all options regardless of individual team member beliefs.

IFSP teams develop an action plan that is creative, flexible, and that uses community resources in response to the family's priorities and concerns. This allows teams to:

- Assist the family in identifying and accessing new resources that will help them meet the needs of their child.
- Explore fully all options for supports and services in the community.

Early Childhood connection providers facilitate Colorado communities that embrace and encourage each child to learn and grow by:

- Communicating how supports and services in natural settings promote the family's and baby's participation and belonging as members of their community.
- Creating opportunities to enhance quality of life.

Families share their stories about possibilities:

Maria and José: Unlimited Possibilities

When she was growing up, Maria was very active, and always dreamed of hiking and playing sports with her own children. When her son, José, was born with a hearing impairment, Maria thought her dream had ended. Her first concern was for José's safety.

At the IFSP team meeting, Maria shared her dreams and concerns with the team. Julie, an early intervention teacher, suggested that José enroll in a toddler gym class at the YMCA. Maria was very nervous, worrying how José would be able to participate and about what other parents might think. Seeing her nervousness, Julie offered to go with Maria to facilitate José's participation.

At the end of the first class, Maria was in tears — they were tears of happiness. Maria had seen her son climbing, jumping and playing with many other children. She found that the other parents were excited to see their children learning sign language to communicate with José.

The gym instructor and other parents offered to support Maria and José at the class, so Maria decided that Julie would only be needed for occasional phone consultation. One family even invited Maria and José to their house for a play session so the boys could practice their skills before the next class!

The IFSP team had created new opportunities for José and his mother. Maria realized she hadn't lost her dream after all. She and José may need extra support now and then, but her IFSP team would be there to help her work it out.

Whitney, Travis and Meredith: The Therapy Ball

As Whitney prepared for her son's IFSP meeting, she was nervous. Travis' physical therapist, Meredith, had told her that she should think about getting a therapy ball so she could work more with Travis at home. The problem was that Travis hated the activities they did with the ball during his therapy sessions. Whitney just couldn't work with the ball at home. Not only did Travis hate the ball, but between work and college, she just didn't have time. Her priorities were for Travis to spend more time with his father, James, and to find a way to work on Travis' motor development that would fit into their busy days.

At the IFSP meeting, Whitney shared the realities of their lives, and also told the team that the family's interests were swimming and riding horses. She had a horse and rode every weekend, but the family wasn't currently swimming because they couldn't afford a membership at the local recreation center.

The IFSP team did some creative thinking with Whitney and developed supports and services that built on the family's strengths and interests. They all felt excited about the ideas they found to meet the unique needs of the family.

For example, the service coordinator connected Whitney to a "hippo therapy" program so she could learn ways to work on Travis' motor development while he was riding horses with her on the weekends. The family also received a sponsored membership to the local recreation center, where Travis and his father could go swimming twice each week. Both Meredith and Whitney were thrilled that the team had found ways that the family could work on Travis' motor needs without having to use the therapy ball after all!

Reflections about Creating Possibilities

Reflections for families:

Do we look for supports and services that will lead to full participation in our family and community life for our baby?

Do we see our child as a whole person with strengths and gifts to offer?

Do we challenge the system when it doesn't meet our needs or doesn't fit with our dream for our child?

Are we willing to take risks?

Do we dream big wonderful dreams for our baby and our family?

Reflections for providers:

Do I focus on supporting the baby's participation in family and community life?

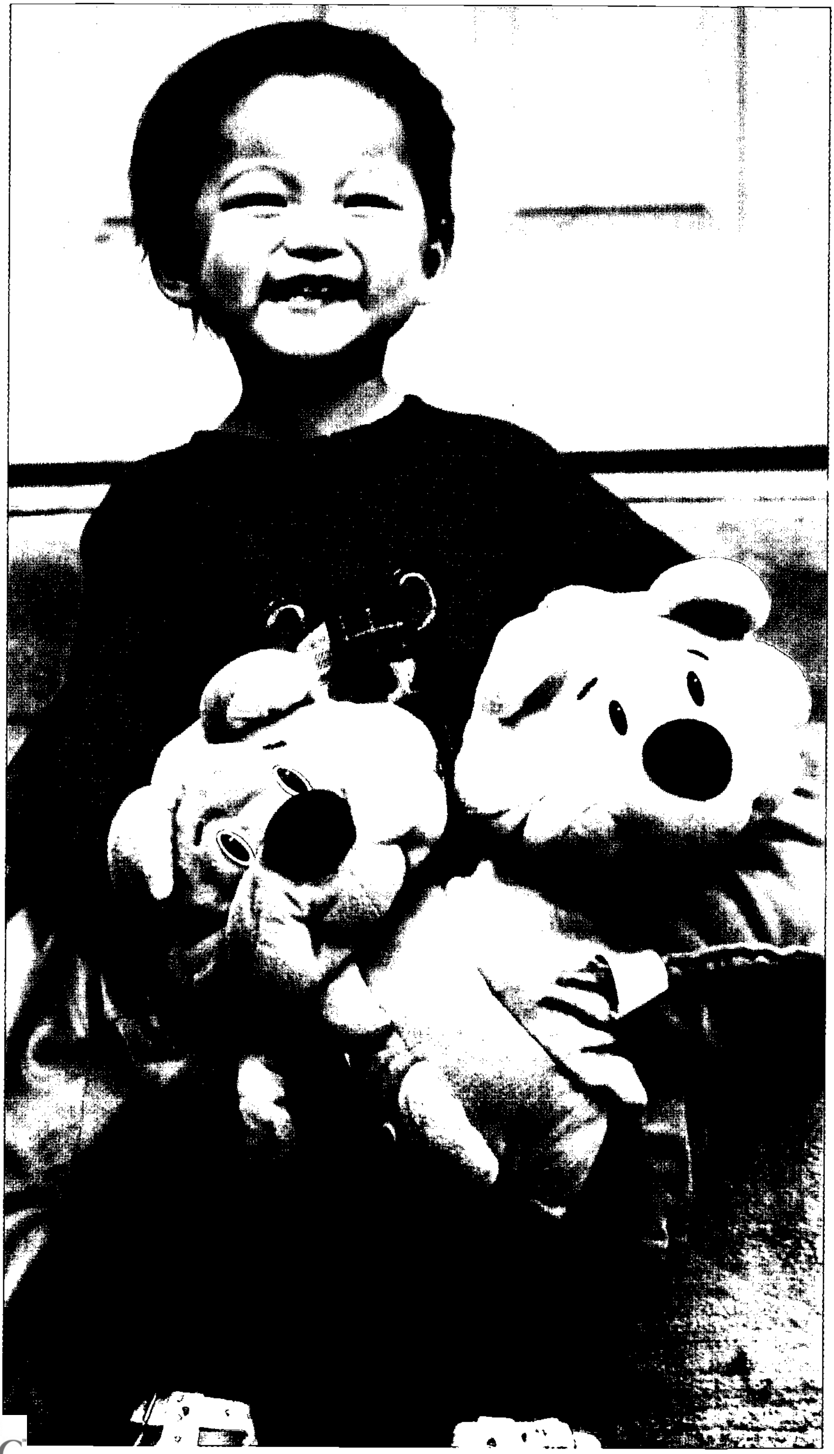
Do I see each child and family as having strengths and gifts to offer?

Do I encourage participation in the planning process by people from the family's community who are not connected in some way to disability?

Are the IFSP processes I participate in creative, flexible and collaborative?

Do I communicate how supports and services in natural settings will meet the developmental needs of the baby and will promote the participation and belonging of the family and baby as members of the community?

Does each IFSP have unique outcomes and strategies that reflect the interests of the family?



Families

> **Families make the best choices when they have comprehensive information about the full range of formal and natural resources in their communities.**

The key ingredient for successful IFSP processes is creating supports and services that are meaningful, respectful and accessible to each family as determined by them.

Successful IFSP teams:

- Allow the family to coordinate as much of their own process as they would like.

- Allow adequate time at meetings to provide information and to discuss all options.

- Assure that all documentation is in language and format that is useful and easy to understand.

- Inform the family about the impact that suggested supports and services will have on them financially (if applicable) as well as the effect implementing the supports and services will have on their daily lives.

- Encourage families to use the same good consumer skills in choosing early interventions that they might use when selecting a child care center or other activity for their child.

- Assure the family's choices are recorded on the IFSP, even when public money is not being used to pay for se supports and services.

Families need a full understanding of each step of the IFSP process, in order to make informed decisions for their child and themselves.

IFSP teams need to:

- Provide each family with an IFSP Workbook*.
- Involve families in every step of the process.
- Use family priorities to guide the work of the team.
- Document the child's strengths and areas of concern in everyday language.
- Develop outcomes, supports and services that address the baby's or toddler's development and/or the family's concerns.

Families need a broad range of information to provide a context for making informed decisions. To assure this, IFSP teams:

- Make connections with other families.
- Provide information about the full range of formal and informal resources in the community in a neutral manner.
- Make sure the family knows who to call if they have questions or concerns.
- Provide information about parent-to-parent support, disability-related or parent support groups and other advocacy organizations.

* To order copies of the IFSP Workbook call (800) 284-0251.

Families share their stories:

Kristy, Emily and Jim: The Happy Baby

Whenever Kristy feels that she is losing power and control to the momentum of her daughter Emily's "disability," she remembers her last IFSP meeting. That day she and Jim, Emily's social worker, were discussing Emily's strengths.

Jim commented on what a happy baby Emily is. Kristy then shared all she had heard about her daughter's "label" — "Babies with Down syndrome are very sweet-tempered, happy and contented. They're not capable of worry or stress."

Jim interrupted Kristy, saying "No! Emily is who she is because of you and your husband! Every child and family is unique. You have created a warm, loving, accepting environment in your home for Emily. That's why she's so happy and contended, and why she is making such great progress!"

Until that meeting, Kristy and her husband had never felt they were really in control of Emily's destiny. After listening to Jim, they now realize that they are in control and that their actions and beliefs set the direction for the kind of life Emily will have, both now and in the future.

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Shelly and Lisa: Checklists and Reality

Late one afternoon, Shelly, the service coordinator for the Fremont family, noticed that Jason Fremont was due for his IFSP review in two weeks. She decided that before she left work that day, she would call his mother, Lisa, to set the date for an IFSP meeting.

When Lisa answered the phone, however, she sounded extremely distraught. She told Shelly she couldn't talk then because she needed to keep the phone line open: one of her other children was ill and might need to go to the hospital. Lisa explained that her husband was out of town, she was waiting for a call from the doctor, and she needed to arrange for someone to stay with her other children. Shelly asked if she could help by making the calls to arrange childcare for the other children. Lisa said that would be very helpful and gave Shelly the phone numbers and details.

After Shelly had made arrangements for the childcare, she called Lisa again. Lisa was relieved because the doctor had just called to say they were going to admit her baby to the hospital.

In the hours that followed, Shelly reflected on how different her interaction with Lisa had been from what she had expected. She called to make a date for the IFSP review, but although that had not been possible, she had been able to lend a hand when Lisa most needed help. Shelly made a note in her calendar to call the following week to see how things were going with the family. At that time, if it felt right, she and Lisa would set a date for the IFSP meeting.

Reflections on Respecting Families

Reflections for families:

Have we explained to the team what is really important to our child and family right now?

Have we asked questions or requested new information if we need it?

Do we speak up when things don't feel right to us?

Do we see ourselves as key people on the team?

Do we believe that we are our child's best advocates?

Reflections for providers:

Do I assure that families have information they need to make informed decisions?

Do I make information available in different languages and formats so it is accessible to all families?

Do I see parent-to-parent connections as positive and make it a priority to make those connections?

Do I provide information about what I believe should happen more enthusiastically than I provide information about other options?

Do I see families as being competent even if they make decisions I do not agree with?

Do I relate a family's stories to my own experiences as a ans of truly listening with the intent to understand?

Relationships

Families have the right and responsibility to make decisions on behalf of their children and themselves.

Children and families are valued for their unique capacities, experiences, and potential.

Many relationships develop during the IFSP process. Positive, respectful, ongoing relationships between the family and the providers are key to the successful development and implementation of the IFSP.

The family's questions, expectations and choices direct the steps in the IFSP process. Family members should have time to think about information (such as evaluation results or options for supports) and ask questions prior to making any decisions.

Families may share their "stories" about the birth of their child, their questions about their child or their every day lives. Family stories help the family and the providers identify:

- Strengths within the family which may be used to support the child,
- Concerns held by the family,
- Interests and activities of family members that may provide information about settings or ideas on which to base supports and services,

- Outcomes for the baby and family that will be unique and meaningful, and

- Strategies for achieving outcomes that enhance the family's current activities.

Providers have a variety of roles and responsibilities in their relationships with families. These include:

- Modeling open and honest communication,

- Being clear about their roles and responsibilities,

- Being willing to address differences by finding common ground,

- Listening openly; screening out their own biases, assumptions or stereotypes trying to fully understand the family's information,

- Providing information on supports and services in ways that promote the family's and baby's participation and belonging as members of their community,

- Providing information about the evaluation results, child development, procedural safeguards and options for achieving the outcomes defined by the family,

- Assuring the family's comfort in participating in every aspect of the process, and

- Assisting the family in identifying what they can provide and where they would like assistance.

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Families share their stories about relationship:

Laurie, Doug and Trevor: The Birthday Party

Laurie and Doug were excited as they planned Trevor's first birthday party. It was a special time, for medical specialists had told them that Trevor wouldn't live until his first birthday. As the date drew closer and they realized what an important milestone this event was, they decided to have a big celebration. Invitations were to be sent to everyone they felt was significant in their lives.

But as Laurie and Doug looked at the list of invitees, they realized that everyone they intended to invite were people who were paid to be involved in their lives. Laurie and Doug had lost touch with the friends they'd had before Trevor was born. After the doctors' appointments, therapy sessions and sleepless nights, there just hadn't been time and energy to spend with their friends.

For the past year Laurie and Doug had found their lives wrapped up in "disability." They wished someone had warned them this was happening — but realized they probably wouldn't have listened. Laurie had reached out to the providers that she and her son spent so much time with; the providers had filled a void in her life.

Although the relationships Laurie has with providers are important, she intends to spend the next year putting those relationships in perspective and re-establishing connections she had lost with friends she had before Trevor was born.

Viveca, Tyrone and Sara: Developing Functional Outcomes Communication

At a recent IFSP meeting, Sara, a speech pathologist, asked Viveca what she would like to see her son, Tyrone, accomplish in the next six months. Viveca responded that she would like Tyrone, then almost two years old, to be able to talk. Sara felt a little uncomfortable, because Tyrone still wasn't saying any words.

Sara asked Viveca to tell her how the family's life would be different — what it would look like — if Tyrone could talk. "I would like to understand what he wants," Viveca said. "Now when he wants something, if I don't understand what he's trying to tell me by pointing or babbling, we both get very frustrated. Tyrone starts crying and I feel so inadequate for not being able to meet his needs!"

Together, Sara and Viveca decided that what would make a significant difference for the family would be a method for Tyrone to let them know his needs and wants. Viveca was excited at the possibility of a communication system that would work right away, but also repeated that her ultimate goal was for Tyrone to be able to talk.

Together Sara and Viveca wrote two functional outcomes:

1. Tyrone will be able to let his mother and others know what he wants using communication signs developed with his mother and the speech pathologist.

2. Tyrone will respond by babbling when someone talks to him.

Reflecting on Relationships

Reflections for families:

Am I taking time to think through the information I am given to make decisions?

Am I being heard by the providers? Do they give weight to my observations, information and ideas?

Do I still have questions I need to ask?

How do I feel about involving these providers in my child's life and my life? How open do I want to be in sharing personal information?

Reflections for providers:

Am I listening to this family with an open mind, ready to learn about their child and their unique situation?

Am I assuring that the family's ideas are heard and their questions are answered?

Am I being clear about my role and my relationship to family members during this process?

Am I being conscientious about following up on the commitments I make along the way. Am I returning phone calls, finding information, and making the contacts and connections I said I would? Am I clear in my communication?

Am I helping to create a plan that is unique to this child and family and that promotes their meaningful participation in their community?

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The Components of the IFSP

The Individuals with Disability Education Act is a federal law that assures all children the right to an education. Part C is the section of the law about children from birth to three. Part C describes the requirements of the law and the intent or "the spirit" of the law including the importance of supporting the child's development in ways that enhance participation in family and community activities.

The written record of the IFSP process includes:

- The child's present level of development;
- The family's concerns, priorities, and resources;
- Outcomes for the baby and family as defined by the family;
- A variety of strategies for achieving the outcomes, including supports and services in natural settings;
- Location of the supports and services;
- Documentation and justification for any supports and services that aren't provided in natural settings regardless of which funding source is being used to pay for them;
- Frequency and intensity of the supports and services;
- Dates that the supports and services are to begin and how long they will last;
- Criteria to be used to determine progress;
- Other services not required under Part C and steps that will be taken to secure them;
- Payment arrangements and activities to secure payment resources, including funding from state and federal government sources, private insurance, local agencies and/or the family;
- The name of the service coordinator; and
- The steps for transition from infant/toddler to preschool services at age three.

An IFSP must be created within 45 calendar days from the family's first contact with Early Childhood Connections.

The child's present level of development:

- Is determined by a team of at least two qualified providers from different disciplines giving their informed clinical opinion, and includes parent reports and observations in familiar settings;
- Determines eligibility for Early Childhood Connections supports and services; and
- Provides a holistic view of the child including strengths and gifts to build upon and areas of delay for setting goals and determining outcomes.

Service coordination:

- Is available immediately upon a family's contact with the Early Childhood Connections system;
- Assures that each step of the process happens in a timely manner, with the family's understanding and agreement;
- Provides accurate information on the law, procedural safeguards, funding sources, and community activities and resources for families and young children; and
- Is provided in a manner that is consistent with the Colorado Service Coordination Guidelines.

Transition plan, which begins six months before the child turns three, includes:

- The child's strengths, likes, dislikes and needs;
- The family's priorities, hopes and goals;
- Choices and options for strategies, supports and services that may be utilized to meet the toddler's and family's needs;
- Ways of sharing important information between settings; and
- Documentation that the family has received and understood information on the difference in rights and entitlements between infant/toddler (Part C) and preschool services (Part B).

Glossary

Augmentative Communication Device: Any item that is used to facilitate a child's ability to communicate with others. This may include such items as a picture board, computer, etc.

Cultural Linguistic Mediator: A person provided to the family at no cost to translate language and/or make sure that the supports and services offered are congruent with the family's culture.

Formal Supports: Supports or services that are provided by someone who is paid for those services.

Informed Clinical Opinion: Used to determine if a child is eligible for early intervention supports and services. Typically informed clinical opinion is based on consensus of a multi-disciplinary team including the family gaining knowledge about the child using a variety of formal and informal methods.

Informal Supports: Naturally occurring elements within the family's community and culture that can be used to support the needs and outcomes identified as priorities on the IFSP.

Natural Settings: Settings that individual families have identified as natural or normal for their families, including the home, neighborhood and community settings in which children without disabilities participate.

Options: The variety of formal and informal supports and services from which a family may choose in order to work toward accomplishing the priorities and outcomes they identified during the IFSP process.

Present Level of Development: A statement of how the child is functioning in each area of development; includes areas of strengths and need.

Primary Language: Language used for communication between family members in their home.

Provider: Any person who provides a service to the child and their family, including preschool and infant teachers, early interventionists, therapists, social workers, etc.

Resources, Priorities and Concerns: The areas identified by the family regarding needs they would like addressed, what is most important to them and what they can contribute toward the implementation of their IFSP.

Supports and Services: Any formal or informal activity listed on the IFSP that will increase the family's ability to enhance the development of their child.

Basic Rights

Each family in Colorado that has a child with a disability is entitled to the following:

Multi-Disciplinary Evaluation
Providers from at least two early intervention disciplines assess a child's strengths and needs in all areas of development to determine eligibility for Part C services and supports.

Individualized Family Service Plan
The IFSP is a planning process used to develop supports and services that best meet the needs of an infant or toddler with disabilities and their family. The components of the IFSP must be documented. A variety of financial resources may be used to pay for the supports and services listed on the IFSP including state and federal government sources, private insurance, local agencies and/or the family.

Service Coordination
Assistance is provided to the family throughout the IFSP process including providing information to the family about the broad range of supports and services available to them, arranging for supports and services, coordinating between agencies and organizations the family chooses to participate with, connecting the family with other families and provide information about the family's rights and procedural safeguards.

Procedural Safeguards
These are processes to ensure the family has information that will allow them to participate fully in the IFSP process, to ensure that all information about them and their child will remain confidential, and to ensure an appeals process for times when the family disagrees with recommendations made by Early Childhood Connection providers.

Procedural Safeguards

Families are entitled to:

Prior Notice

Receive prior notice about dates of meetings, changes that Early Childhood Providers want to make and the family's right to say "yes" or "no" to those changes.

Native Language

Receive all information and explanations in writing and everything that is spoken or written translated into their native language.

Informed Consent

Have complete, comprehensive information and explanations about all the options that are available to them and their child.

Confidentiality

Complete confidentiality regarding all information about their child and family.

Access to Records

Have access to all records including the right to receive copies of records and reports and to change or add to any record they think is wrong.

Process to Appeal Decisions

Disagree with recommendations and decisions that professionals make about their child and family, and to have access to a process to resolve any disagreements the family might have with Early Childhood Connection providers (including mediation services, if desired).

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These guidelines were created by parents, providers, community members, Lead Agency staff, representatives from school districts and others. This committee was called together by the Colorado Interagency Coordinating Council to develop this document to guide our work as Colorado implements Part C if the Individuals with Disabilities Education Act (IDEA).

Early Childhood Connections
for Infants, Toddlers & Families

The Values of the Colorado Interagency Coordinating Council

Creative, flexible, and collaborative approaches to services allow for individual child, family and community differences.

Community differences are enhanced by recognizing and honoring the diversity among all people.

Families make the best choices when they have comprehensive information about the full range of formal and natural resources in their communities.

Families have the right and the responsibility to make decisions on behalf of their children and themselves.

Children and families are valued for their unique capacities, experiences and potential.

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