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## Family2Family to Host Workshop: “Understanding the Effects of a Diagnosis on the Family” this Spring

When an infant or toddler is diagnosed with a disability, families experience a wide range of emotions on their journey of acceptance and, eventually, joy.

To better understand this experience for families and to learn how to best support families, F2F and FC are collaborating to provide Cultural Sensitivity workshops this spring. The first of the series features parents of children with disabilities sharing their stories of overcoming challenges, what they’ve learned on their journey, and what they wish providers knew.

EIS providers are encouraged to attend for professional development hours to assist them in helping parents express their child’s abilities as well as needs as parents learn to advocate for their child and help their child develop and learn.

Workshops to be offered at no cost to participants in various regions of the state. Those interested register in CDS.

## How EI under Part C Differs from Traditional Therapy

From *Early Steps*, the Louisiana Part C Program

Early Intervention	Traditional Therapy
<ul style="list-style-type: none"> <li>▪ <i>Natural Environment: takes place in the home, community, or child care center.</i></li> <li>▪ <i>Works with care givers to teach them how to help their child during daily activities.</i></li> <li>▪ <i>Intervention is woven into the child’s and family’s daily routines.</i></li> <li>▪ <i>Services are determined based on family priorities and what is needed to meet functional outcomes on the IFSP.</i></li> <li>▪ <i>Service levels are based on the amount of time needed to assist the caregiver in enhancing the development of the child within typical activities.</i></li> <li>▪ <i>Takes advantage of the way children learn naturally in their everyday experiences with their families as intervention happens between provider visits.</i></li> <li>▪ <i>Functional outcomes are linked to typical child activities and cross domains; providers may use a team approach.</i></li> </ul>	<ul style="list-style-type: none"> <li>▪ <i>Clinical Model: takes place in a therapy room, a clinic, or hospital setting.</i></li> <li>▪ <i>Provider takes the child into a separate room to perform therapy services.</i></li> <li>▪ <i>Works only with the child, families may or may not be included.</i></li> <li>▪ <i>Services are based on deficit areas on formal evaluations that determine what the child qualifies for.</i></li> <li>▪ <i>Service levels are recommended outside of the IFSP team meeting and are directly related to the amount of time the therapist spends with the child</i></li> <li>▪ <i>Services only occur during therapy sessions.</i></li> <li>▪ <i>Therapy goals on an IFSP are domain specific and not linked to typical child routines; therapist does not collaborate with other providers.</i></li> </ul>

# Writing Participation-Based IFSP Outcome Statements

from *Briefcase*, vol 2, iss 1. Sheldon & Rush. Mar 2009.

As our state's Part C program shifts to align with IDEA, Part C requirements, OSEP guidelines, and EI best practices, EI professionals working with families develop Individualized Family Service Plan (IFSP) outcome statements that are participation-based and related to child learning within everyday opportunities.

## Three Failsafe Steps for Writing Participation-Based IFSP Outcome Statements

- 1. Gather information** about activity settings, routines, interests, current participation, and desired participation or possibilities for successful child participation in real-life situations.
  - ✓ Listen for possible IFSP outcome statements during conversations with family members and care providers as they share their priorities, questions, and ideas.
  - ✓ If a child spends time in a child care setting or substantial time with an extended family member or friend, with parent permission these care providers should be included in the process. Remember, when talking about everyday activities and ideas about how the child's participation might prove to be more successful or helpful to the family members, parents and other care providers *do know* what they would like to see.
  - ✓ If a parent states a concern that is deficit-based or skill specific, for example, "I want my child to walk," then the EI team is prepared to probe further into how the delay affects the child's participation in existing or desired activities. The EI team can discuss the implications of not walking on everyday activities. Asking the family to imagine one of their own specific activities (like playing in the backyard with the puppy) in which the child who at the present time cannot walk and compare how the activity would look or change if the child could walk on her own can be an effective strategy. A parent might say, "Instead of carrying her down the steps off the porch, she could walk down on her own and I could carry out the toys we would play with," or "She could go after the puppy when it wanders off, instead of screaming and crying." Each of these parent statements could be written as an IFSP outcome statement. In addition to walking, each of these outcome statements involve elements of play, communication, social interaction, cognition, and motor development that could be expressed and enhanced during playing in the backyard with the puppy.
- 2. Observe families and children** and care providers engaged in real life activities and situations prior to the IFSP meeting.
  - ✓ Observe children across different settings, people, and times of day. Observing during activity settings in which the child is successful as well as when the child is challenged provides information directly applicable to writing quality IFSP outcome statements.
  - ✓ Involve parents and other care providers in the observations with the child. Observation in real-life activity settings involves the early interventionists stepping back and allowing family members and other care providers to demonstrate how things currently happen, what they usually do, and very importantly what they've already tried in similar situations.
  - ✓ Use ecological assessment to observe a child during child participation in everyday activity settings. Ecological assessment requires the following: (1) a comfort level with watching others as they go about what they would

typically be doing if the practitioner was not present, (2) knowledge of typical child development, (3) knowledge of responsive parenting and teaching, (4) ability to perform task analysis and think on one's feet while observing others, and (5) a willingness to be open to the possibilities of how families and care providers go through their everyday lives.

**3. Document quality IFSP outcome statements** that are discipline-free. An IFSP document should not contain separate occupational therapy goals, physical therapy goals, speech-language therapy goals, or education-based goals.

- ✓ Avoid the use of jargon and technical terms and write outcomes as close to the way the family states their goals as possible so that everyone involved can use the plan and be able to informally assess progress and determine “How will we know when we get there?” Practitioners may have concerns regarding measurability of participation-based outcomes because they've had prior experience with writing Individualized Education Program (IEP) outcomes that require specific measurability criteria (e.g., three of five times for five consecutive days; 100% of the time; within six months; or every time she wears her coat to school). When writing quality IFSP outcome statements, the parents determine whether or not the IFSP outcome has been achieved. When developing the outcome statement, it is important to discuss the outcome in such a way that everyone involved feels comfortable with how progress will be measured.
- ✓ Use a special occasion or life event such as a birthday or holiday or a real-life point in time such as when grandma visits this summer or by the time school starts this fall (for the siblings) as the timeline on an IFSP outcome statement. This strategy helps care givers in thinking in “real time” about the possibility of achieving outcomes within the context of the big picture of their family life. The time period of 3-6 months is meaningful to most early interventionists because it is the time period between reviews of the IFSP. For most

families, however, this time period can be ambiguous.

- ✓ Avoid the following passive words when writing child-focused, participation-based IFSP outcome statements: (1) tolerate, (2) receive, (3) increase or decrease, (4) improve, and (5) maintain. These words are not congruent with functional, meaningful, quality outcome statements. These words are generally descriptors of passive types of activities (e.g., tolerate a certain position; tolerate something being done; receive a specific service or treatment; maintain range of motion; and maintain eye contact) or are reflective of some type of skill enhancement or physical trait (e.g., increase range of motion; decrease spasticity; improve behavior; increase attention span; decrease tantrums; and increase oral-motor control). For quality child-focused IFSP outcomes to reflect enhanced participation, words that describe action, engagement, enjoyment, and involvement are required.
- ✓ Apply the “action verb rule.” The action verb in a child-focused, participation-based outcome statement should be a functional concept not a specific skill. For example, consider a situation in which a particular family shared with the early intervention team that their son, Sanjay does not like taking a bath. They further describe bathtime as a rough time for the entire family. The family feels that Sanjay's inability to sit makes him uncomfortable and frightened so that he cannot enjoy his bath. A possible outcome statement for Sanjay could be, “Sanjay will participate in bathtime by **sitting** in the bathtub during his bath.” The action verb is “sit” in this IFSP outcome statement. Sitting is a skill that Sanjay does not currently possess. Sitting is certainly an important skill, but a caution would be that the focus could be placed on the act or skill of sitting instead of Sanjay's enjoyment of and participation in bathtime.



# EI FAQs – Part 1

**Q. Are recent IFSP updates/reviews being done because of budget issues? How does the service coordinator (SC) and other members of the IFSP team explain the purpose of recent IFSP updates/reviews to the family?**

**A.** Every IFSP, regardless of pay source, must be reviewed and updated to ensure that it meets IDEA, Part C requirements, OSEP guidelines, and EI best practices. The IFSP team explains the purpose of the IFSP review/update with families. They may say: *“The purpose of the IFSP update/review is to review the existing IFSP to ensure that the IFSP*

- ✓ Follows the best practices
- ✓ Builds on and enhances the child's current learning and
- ✓ Participates in typical and family activities
- ✓ Identifies the resources a child and family have (e.g., caregivers, community resources).
- ✓ Works with caregivers to build caregivers' ability to use strategies to assist the child's learning.
- ✓ Incorporates intervention strategies into the child's daily life if the child has many opportunities to practice new strategies in context because that's how children learn best.
- ✓ Includes at least one family outcome (goal for the adult caregiver) in the IFSP.”

**Q. What does a service coordinator (SC) say to a family if the provider chosen has no Part C funding left? OR, what does the SC say if she knows that the chosen area provider is out of Part C funding, but the family chooses that provider?**

**A.** If family chooses a provider that has no Part C funding left, the SC could say: *“The Connections Program has limited funding which is allocated to \_\_\_\_\_ area providers. Unfortunately the provider you have chosen has no Part C funding at this time. You can, however, pick one of the other providers who does have funding at this time.”*

**Q. When must the Functional Family Assessment be completed?**

**A.** The Functional Family Assessment is required for every IFSP meeting. For IFSPs being updated, the assessment is required for the update meeting. The assessment is also required as part of the IFSP update/review process.

The assessment is generally completed as part of intake, but may be completed at the IFSP meeting (initial or review). The assessment must be completed **before functional goals/objectives are created on the IFSP.**

**Q. What if the family refuses to participate in the FC Child & Family Assessment?**

**A.** Most families love to talk about their child and family, but parent participation is voluntary, and families may refuse to participate in the assessment interview by completing/signing a non-participation form which the SC uploads into CDS. If the SC clearly explains the purpose of the assessment and the benefits, few families will choose to not participate as the information from the assessment helps the team create the best possible IFSP for that child and family..

**Q: Where do we put the completed FC Child & Family Assessment?**

**A.** The completed FC Child & Family Assessment is scanned/saved and uploaded into the child's CDS file. The paper copy is placed in the child's traditional file.



## Outcomes on the IFSP must be family-centered and functional to meet Part C requirements.

**Family-centered** outcomes are the priorities, concerns, and goals a family has for their child and family as a whole. They are created **with the family after assessing what activities are meaningful to the child and family** in the newly required FC Child & Family Assessment completed before the IFSP is created. In most states, IFSPs are required to have at least two family-level (parent) goals/objectives on the IFSP in addition to the child's outcomes – the new requirement in Arkansas is one parent goal on the IFSP.

**Functional** goals and objectives cross domains and build life skills that the child needs in order to function as a full and active participant in his/her typical daily life. Functional goals and objectives enhance the child's ability to participate in **functional activities** (feeding, dressing, moving around, communicating, playing, participating in daycare, etc). Functional outcomes also **enhance the family's ability to care for or to engage in activities with their child** and expand on activity settings in which the child already participates successfully and support a child's development in the

### 3 Global Child Outcomes:

- (1) acquisition and use of knowledge and skills
- (2) uses appropriate behavior to get needs met
- (3) positive social-emotional skills (relationships)

### Formula for Functional Outcomes:

1. Obtain goals, concerns, "problem areas" of the day from family assessment.
2. Find out what routines are affected/involved (bedtime, lunch, errands)
3. Write the 1<sup>st</sup> half of the outcome using the formula:  
child's name **will participate in** specific activity/ies **by** action verb**ing**
4. Include observable behavior to determine mastery in the 2<sup>nd</sup> half of the outcome using the formula:  
**We will know** child's name **can do this when he/she** specific skill or behavior
5. Add **criteria in ordinary language** to indicate fluency, maintenance, measurement, or generalization such as an amount of time, an amount, or across different environments or routines.

**EXAMPLE:** Stacy **will participate in** lunch and dinner times **by** **chewing** her food and **moving** it from side to side with her tongue. **We will know** Stacy **can do this when she** eats **1 cup of food in this way, 1 time at lunch, 1 time at dinner, and 1 time in a restaurant over a period of one week**

## Did YOU Know?

Early Intervention under Part C of IDEA has, as its primary focus education? These programs fall under the Office of Special Education Programs (OSEP). OSEP has established the following outcomes (or goals) for infants/toddlers participating in states' early intervention programs operating under Part C:

- ✓ Children have positive social relationships
- ✓ Children acquire and use knowledge and skills
- ✓ Children take appropriate action to meet their needs

Early intervention under Part C of IDEA seeks to build functional, foundations skills to help infants/toddlers with a developmental delay or disability to be full, active participants in home and community life. Programs are also expected to provide consultation and training to the adult caregivers in the infant's/toddler's life so that caregivers can assist the child's development within typical child activities.

Providers unable to serve an infant/toddler and his/her family for any reason (no openings, funding issue, etc) must refer the child back to the State Staff Service Coordinator in the area in which the family resides. To do that in CDS, enter a new referral on the infant/toddler and choose "state staff person." Enter in the notes are the reason for referring back.

Any child leaving First Connections (EI Under Part C) must have all exit requirements completed in CDS. Exit requirements can be found on the Transition Tab. All children leaving the program for any reason are transitioning somewhere, and these steps must be completed:

- \* COS ratings at Exit
- \* Outcomes ratings (providers participate, family participates)
- \* If the family is "opting out" and leaving Part C – a parent choice form signed and dated
- \* Transition plan in CDS (if the child is not Part B eligible or potentially eligible, mark not eligible in CDS and continue). NOTE: Children who are not approaching third birthday will not have a transition conference.