

First Steps

Module 2: Eligibility Determination

Module 2 Tab 1: Introduction

Module 2: Eligibility Determination provides details regarding the referral, intake, evaluation, assessment and First Steps eligibility determination process. First Steps is Missouri's early intervention system for infants and toddlers, birth to age 3, who have delayed development or diagnosed conditions that are associated with developmental disabilities. The content for this module includes the philosophy of early intervention, the federal requirements of Part C of the Individuals with Disabilities Education Act (IDEA), and the procedures for families and professionals.

Module 2: Eligibility Determination is required for all individuals who provide services in the First Steps program. Other individuals who are interested in learning more about early intervention and the First Steps program are welcome to review the module.

OBJECTIVES FOR MODULE 2

1. Define the following terms and describe how they relate to the First Steps program.
 - Assessment
 - At-risk
 - Criterion-referenced test
 - Developmental Assessment of Young Children (DAYC)
 - Developmental delay
 - Disability
 - Eligibility criteria
 - Evaluation
 - Informed clinical opinion
 - Medical/diagnosed conditions
 - Multidisciplinary
 - Newborn conditions
 - Norm-referenced test
 - Notice of Action/Consent
 - Providers
 - Primary referral sources
 - Qualified personnel
 - Screening
 - Service Coordinator
 - Standardized test
2. Identify the essential components and the steps in the referral, intake and eligibility process.

3. Name Missouri's criteria for determining eligibility for First Steps.
4. Name the three eligibility decisions and how to determine eligibility for each.

INTRODUCTION

The Federal regulations for Part C of IDEA require a public awareness program, which focuses on the early identification of children who are eligible to receive early intervention services. Public awareness includes the preparation and dissemination of materials to all primary referral sources, especially hospitals and physicians, on the availability of early intervention services. The public awareness program must provide information to the public about the State's early intervention program; the child find system, including the purpose and scope of the system; how to make referrals and how to gain access to a comprehensive, multidisciplinary evaluation, and other early intervention services; and the central directory.

Another requirement of the Federal regulations is a comprehensive child find system, which must include the policies and procedures the State will follow to ensure that all its infants and toddlers who are eligible for services under Part C are identified, located, and evaluated. The system must provide for an effective method of making referrals by primary referral sources; ensure that children are referred as soon as possible, but in no case more than seven days, after a child has been identified; and include procedures for determining the extent to which primary referral sources disseminate the information to parents of infants and toddlers with disabilities.

First Steps Primary Referral Sources

- Hospitals, including prenatal and postnatal care facilities;
- Physicians;
- Parents; *
- Child-care programs and early learning programs;
- Local educational agencies (including special education and Parents as Teachers) and schools;
- Public health facilities;
- Other public health or social service agencies;
- Other clinics and health care providers;
- Public agencies and staff in the child welfare system, including child protective service and foster care;
- Homeless family shelters; and,
- Domestic violence shelters and agencies.

*Note: Family members, friends or neighbors are not primary referral sources.

First Steps is operated through contractual agreements in regional offices known as the System Point of Entry (SPOE) and they provide service coordination, intake and eligibility determination, as well as all local administrative activities for the program. Once the SPOE receives a referral, a service coordinator is appointed within 2 business days. Within 45 days after the SPOE receives a referral they must complete the referral, intake, and evaluation/assessment activities as well as the development of the initial Individualized Family Service Plan (IFSP).

First Steps operates a toll-free statewide referral line. To make a referral by phone, call:

866-583-2392

A standardized referral form has been developed for use by all referral sources and may be faxed or mailed to the local SPOE.

Primary referral sources can also make referrals to First Steps by entering information about the child and family in the online system otherwise known as WebSPOE.

What Does the IDEA Say?

Mandatory Referrals to First Steps include:

- Referrals from Child Abuse Prevention and Treatment Act (CAPTA) – Part C of IDEA incorporates a requirement of CAPTA. Staff of the Department of Social Services, Children’s Division, must refer to First Steps any child under age three who has been involved in a substantiated case of child abuse or neglect. The children are not automatically eligible for First Steps, but must be referred. First Steps staff will address CAPTA referrals in the same way as all other referrals received.
- Referrals for Prenatal Drug Exposure – Part C of IDEA requires children under the age of three identified as affected by illegal substance abuse, or withdrawal symptoms resulting from prenatal drug exposure, be referred to First Steps. The children are not automatically eligible for First Steps, but must be referred. First Steps staff will address prenatal drug exposure referrals in the same way as all other referrals received.

Following the referral to First Steps, the intake process begins. The following information is shared during the intake process with every family: early intervention philosophy and parent participation, detailed information about First Steps and the 45-day timeline, a copy of the Parental Rights Statement, family cost participation and insurance mandates.

Parent Perspective of Service Coordination

This video depicts a parent describing various activities and interactions with her service coordinator.

BETH'S STORY

(Continued from Module 1. Reminder: Beth is a recent graduate who is learning about the First Steps program as she becomes a new First Steps provider.)

Now that Beth had a better understanding of the philosophy, federal requirements, and an overview of the First Steps program, she was ready to find out more details about the First Steps process. It would take more than just a general understanding of the program for her to become a competent provider. Although her goal was to learn everything about the entire process, she decided to start with the first part of the process; referral, intake, and eligibility determination.

“If I can get all of that figured out today, I’ll be ready for the next piece tomorrow,” said Beth.

A more confident Beth emailed Maria, a provider she met previously. She wrote: “Hi Maria, I’m still trying to figure out all of the steps in the First Steps process. Do you have any time to talk with me about it? I’d be happy to take you to lunch if you have time. I really want to become a First Steps provider, but there is still so much more for me to learn. Is there a time that works for you?”

Maria responded a few minutes later. “I have time tomorrow from 11:15 to 1:00 if that’s ok. Let’s meet at Bill’s Gourmet Sandwiches.”

Beth was waiting at the restaurant when Maria arrived. “Thanks so much for meeting with me. There’s just so much to know. How do you remember it all?”

Maria laughed. “It seems like a lot right now because you aren’t doing it, you’re just reading about it. After you’ve gone through the process with a few families you’ll find it’s much easier to remember. Let’s order and then I’ll talk you through the process – at least I will start. We probably won’t have time get through everything, but I’ll be happy to meet again – of course over lunch!”

“Let’s start at the beginning of the process with referral. Referral is the first “service” that a child and his/her family receive from First Steps. Children can be referred to First Steps by lots of different people. It’s usually the child’s parents, but doctors, Parents as Teachers educators, and child-care providers can all refer a child. Pretty much anyone who has a concern can refer to First Steps except for family members, friends or neighbors. Referrals are made to the SPOE in the region where the child lives. Keep in mind a referral to First Steps can be made in a variety of ways, including fax, mail, phone, or online.”

“Does it take a long time to learn about all of the forms used in First Steps?” asked Beth.

“It does take a while,” responded Maria. “The Service Coordinator handles most of the forms though.”

Maria continued, “A referral occurs when a primary referral source contacts the SPOE with developmental concerns or medical information about a child who is birth to 3 years old. The referral source provides contact information for the family and the SPOE contacts the family.”

“What if the referral source is a parent; does that change anything?” asked Beth.

“Not really,” stated Maria. “If the referral comes from a parent, the SPOE still collects relevant information. The SPOE must determine, based on the information obtained during the initial contact, whether they should proceed with the referral. At this point, and actually, throughout the process, a parent may decide not to proceed since First Steps is a voluntary program.”

“I’ve been noticing when I go to the grocery store that there are a lot of people who speak languages other than English. What happens if a referral is made for a non-English speaking family?” asked Beth.

Maria replied, “Good question. If neither parent understands or speaks English, then a translator must be used for all discussion regarding the intake and eligibility determination processes. This would include a sign language interpreter if the parents sign rather than speak. I’ve only had a couple of families where we used translators. It was really interesting and took quite a bit more time. It works best when the translator really understands First Steps and how the program works.”

“OK, once the referral is made what happens next?” asked Beth.

“Remember, this all happens before you, as a provider, are involved,” replied Maria. Beth nodded.

“Okay,” Maria continued. “Once a referral is made, the SPOE will make an initial call to the family. Usually the first contact is made by phone. During the phone call, the SPOE provides information about the program and eligibility criteria. They also gather more information about the reason for the referral.”

“What if the family doesn’t have a phone?” asked Beth.

“If the SPOE is unable to contact the family by phone, either because the family doesn’t have a phone, or for whatever reason can’t be reached by phone, the SPOE sends a letter to the family,” said Maria. “The letter contains contact information for the SPOE as well as information about First Steps.”

The Initial Contact

The purpose of the initial call is to:

- Introduce the program, briefly;
- Share eligibility criteria;
- Discuss the reason for the referral; and,
- Schedule the intake visit.

“Okay, I think I am getting the picture of what happens before I am introduced as a provider,” said Beth. “I am anxious to learn more about the first visit with the family, I think that’s called the ‘intake’ visit?”

“Yes,” said Maria. “During the intake visit, the Service Coordinator again introduces the family to the First Steps program. First Steps may not be the type of program that the family expected, so it is essential to spend time explaining the program philosophy and goals. Since most people are familiar with a medical model of services, explaining how things work in First Steps is really important.”

Maria continued, “Service Coordinators are careful to listen to families and may need to explain things more than once because there are several things to cover in the first visit with the family. It is important to respond to their questions and to make sure that the family understands what is asked of them, including their involvement in activities and meetings. We want every family to be fully informed when they give consent or when they choose not to.”

The Intake Visit

The following information is shared or explained during the intake visit with every family:

- Voluntary Participation
- First Steps Program Brochure
- Early Intervention Team Brochure
- Parental Rights Statement
- System of Payments

“This sounds very formal,” replied Beth.

“It sounds formal, but it’s not. Remember that Service Coordinators are skilled in how to explain this to families. It often feels like a supportive discussion and even parents, who are very nervous in the beginning, often begin to be more relaxed when they realize that no one is there to judge them or tell them how to do things. Service Coordinators really do want to help the family in whatever ways they can.”

“I think so too. What happens next in the visit?” asked Beth.

Maria replied, “After explaining the program and answering questions, the Service Coordinator asks if the parent wants to participate in First Steps.”

“Why would a parent choose not to participate?” asked Beth.

“Well, occasionally, there are families who decide they don’t want to participate because they would rather go to a clinic or hospital to receive services,” explained Maria.

“Sometimes families don’t want to complete the forms and sometimes families don’t want professionals in their homes. Regardless of the reason, participation is their choice.” Maria continued, “We just need to make sure that the family understands the potential effect of not participating in First Steps and also inform them about the Parents as Teachers program and other available services in their community. Linking parents to ongoing developmental services is important for all referrals, but especially those who decline services at any point in time. We also make sure that we tell them that until their child turns 3, they can come back and start the First Steps process again.”

“Often families need some time to review all of the information shared at this first visit,” explained Maria. “We can’t start the evaluation of the child to determine eligibility until the parent signs the consent to evaluate. This form is called the Notice of Action/Consent.”

“How long do parents wait to sign this form?” asked Beth.

“It depends,” replied Maria. “Some families want to sign right away and get the process moving as quickly as possible. Sometimes they may want a day or two to think it over and talk with other family members or friends. Either way, we have to make sure they understand what they are signing and that even if they give consent, they can stop the process at any time.”

Beth asked, “What happens after the consent form is signed?”

“If the parent signs the consent to evaluate,” explained Maria, then the Service Coordinator discusses the family’s questions or concerns about their child’s development and collects information about the child’s medical history and the child’s developmental status.”

“What happens if the parent does not sign the consent form?” asked Beth.

“There are parental rights that apply throughout the First Steps process,” said Maria. “If consent to evaluate is not given by the family, the Service Coordinator needs to make sure that the family is fully aware of the options and understands that their child will not be able to receive early intervention services without being evaluated for eligibility. ”

Then I think we can pick up this green part that used to be in the beginning.

“I imagine that this would be really stressful time for families and that sometimes it could be overwhelming or emotional for parents in this first meeting.” said Beth.

“Yes. Usually these meetings happen in the family’s home, so they feel safer about showing emotions. Again, we want to be supportive. Families shouldn’t be expected to repeat their “story” multiple times, although share their story at this time is often helpful for them as well as for the Service Coordinator.”

Beth nodded.

“Information from the family about the child can be used to assist in the eligibility determination process,” explained Maria. “Parent reports and documentation from previously conducted assessments or services can serve as valuable sources of information. This is especially true for infants referred from Neonatal Intensive Care Units (NICU) or other hospital programs. These infants generally have a wealth of diagnostic information that has been developed. For older children, information from childcare, Parents as Teachers, and/or Early Head Start programs may also contain important and relevant information.”

“How does the Service Coordinator obtain all of that information?” asked Beth.

Maria replied, “A Release of Information (ROI) form must be signed by the family to obtain existing records for each source the family designates. Of course, families decide which information to share and who to share it with.”

“Gosh, there are a lot of things going on in this meeting with the parent. I didn’t know all of this took place the first time the parent meets with someone from First Steps!” exclaimed Beth. “How much of this information from the intake visit is used for eligibility determination?”

“That’s a good question, and it takes us to the next step: eligibility. Let’s pick up there tomorrow when we meet.” Maria asked “Does that sound ok?”

“Yes, thank you,” Beth replied.

REFLECTIVE QUESTIONS

Think about the following questions as you reflect on the introductory material in this section of the course:

1. Can you think of at least 4 additional referral sources besides parents and physicians who can make referrals to First Steps?
2. Why do you think is it important to explain to the family the First Steps philosophy at the initial contact and intake visit?
3. What are some of the reasons you think a family might choose to not participate in First Steps?
4. What information should be provided to the family if they choose not to participate in First Steps?

Module 2 Tab 2: Newborn/Medical Conditions

First Steps eligibility criteria is based on the state definition of a diagnosed physical or mental condition associated with developmental disabilities or that has a high probability of resulting in a developmental delay or disability. Missouri has adopted a list of conditions that meet the definition of “diagnosed physical or mental condition that have a high probability of resulting in a developmental delay.” This list of conditions is broken into three categories: newborn conditions diagnosed at birth or within 30 days post birth, diagnosed conditions and developmental delay.

Newborn Conditions for a child referred prior to 12 months of age with a birth weight of less than 1,500 grams with one or more of the following conditions diagnosed at birth or within 30 days post birth:

- APGAR score of 6 or less at 5 minutes
- Intraventricular hemorrhage (IHV) (Grade II, III, or IV)
- Any Positive Pressure Ventilation greater than 48 hours, including ventilator or oscillator
- Resuscitation/code-event requiring chest compressions

Diagnosed Conditions for a child referred prior to 36 months of age, include, but are not limited to, the following genetic conditions:

- Autism Spectrum Disorders
- Chromosomal Trisomy (Down syndrome, Edwards, Syndrome, Patau Syndrome)
- Craniofacial Anomalies (Cleft Lip, Cleft Palate, Cleft Lip/Palate)
- Disorders of the Nervous System (Cerebral Palsy, Encephalopathy, Epilepsy, Hydrocephalus, Infantile Spasms, Macro/Microcephalus, Periventricular Leukomalacia, Seizure Disorder, Shaken Baby Syndrome, Spina Bifida, Stroke, Traumatic Brain Injury)
- Disorders Related to Exposure to Toxic Substances (Fetal Alcohol Syndrome, Lead Poisoning Level >10 µg/dL)
- Infections/Viruses/Bacteria (Acquired Immune Deficiency Syndrome, Cytomegalovirus, Herpes, Rubella, Syphilis, Toxoplasmosis)
- Other Chromosomal Abnormalities (Angelman Syndrome, Cri-du-Chat Syndrome, DiGeorge Syndrome, Fragile X Syndrome, Triple X Syndrome, Williams Syndrome)
- Other Genetic/Congenital/Metabolic Conditions (Cyanotic Congenital Heart Disease, Hypoplastic Left Heart Syndrome, Muscular Dystrophy – Duchenne Type, Noonan Syndrome, Phenylketonuria (PKU), Pierre Robin, Tetralogy of Fallot)
- Sensory Impairments (Blind, Deaf, Hard of Hearing, Visually Impaired)
- Severe Attachment Disorders

Other Diagnosed Conditions for a child referred prior to 36 months of age include conditions known to be associated with developmental disabilities. In order for other diagnosed conditions to be considered for eligibility there must be an informed clinical opinion provided by Board-certified neonatologists, pediatricians, geneticists, pediatric neurologists and/or other pediatric specialists. These physicians may refer a child by indicating the specific condition and documenting the potential impact of the condition in any of the five developmental areas. Additionally, the professional should describe what developmental issues are likely to occur as a result of the condition. This, combined with other information obtained through the intake process, should be sufficient for determining eligibility.

Important: Children with confirmed newborn or medical conditions do not need a test in order to determine eligibility; however, an assessment identifying the child's strengths and needs in all five developmental domains, including hearing and vision information, must be documented prior to the initial IFSP meeting.

What Does the IDEA Say?

According to Part C of IDEA, the initial assessment of the child must be conducted by qualified personnel and include the following:

1. a review of the results of the evaluation of the child unless medical records confirmed eligibility
2. personal observations of the child
3. the identification of the child's needs in each of the developmental areas
 - cognitive development
 - physical development, including vision and hearing
 - communication development
 - social/emotional development
 - adaptive development

BETH'S STORY

“Okay, First Steps can receive referrals for children birth to 3 years old,” said Beth. “How is the process different if the child is a newborn versus if the child is a 1 year old?”

“Good question,” responded Maria. “There are two groups of children that can be served by First Steps: children who have developmental delays and children who have a newborn or medical condition. For children referred because of a possible delay, and the SPOE has reason to suspect a delay, an evaluation will have to be conducted to determine eligibility. If the child shows age appropriate skills and behaviors, the parents will be given that information and informed of community resources. Is that clear? Babies who are referred due to newborn or medical conditions have a different process.”

“Tell me more about the newborn and medical conditions first, and then let’s talk about developmental delay,” said Beth.

“Okay, let’s start with newborn conditions,” said Maria. “For children referred due to newborn conditions, there is usually sufficient existing information about the child to confirm whether or not the child is eligible. Those children don’t have to go through a testing process to determine eligibility. The Service Coordinator has to collect the medical records that confirm the child’s status at the time of birth, or within 30 days of birth. The Service Coordinator also has to make sure that the referral to First Steps was made before the child is 12 months of age.”

“It seems like this process could take a long time, especially if you have to obtain medical records. I remember someone telling me about the 45-day timeline, and all of these activities are still within that timeline, correct?” asked Beth.

“You’re right,” responded Maria. “It can sometimes be hard to collect and schedule everything in such a short time. But the initial IFSP meeting must be held within 45 calendar days from the date of referral. This 45-day timeline includes the referral, intake, and eligibility determination processes.”

“What happens if the family has to go out of town, or someone is sick, or something like that?” asked Beth.

“The timeline can be extended if the family requests an extension for a reason such as those,” said Maria.

“If that happens, the events are documented by the Service Coordinator. Keep in mind the timeline shouldn’t be extended because the SPOE was not able to get everything done in time or because a provider could not be located to do a test. Occasionally that happens, but usually everyone works together to make sure the timelines are met.”

Beth thought for a minute. “Ok, I feel like I got us a little off track with the timeline. Where were we in the process?”

“That’s okay,” said Maria. “I remember. We just finished talking about the newborn conditions, so now we’re onto the medical conditions. There is some similarity between them though. If a child has a medical or newborn condition, the Service Coordinator must obtain written documentation from a physician who can confirm the child’s condition. If she gets more information from that professional, that will only help with the initial assessment.”

“You might notice that the medical conditions listed in the eligibility criteria are limited,” said Maria.

Beth nodded.

“The list is not an exhaustive list of all conditions,” explained Maria. “Other conditions not listed in the eligibility criteria, but known to be associated with mental retardation or developmental disabilities, should be considered for eligibility. The decision must be based upon informed clinical opinion by Board-certified neonatologists, pediatricians, geneticists, and/or pediatric neurologists.”

“Who gives this clinical opinion?” asked Beth.

“When obtaining information from one of these physicians, s/he must complete the Physician Informed Clinical Opinion form to indicate the specific condition and document the potential impact of the condition in any or all of the five developmental areas.”

“Are there any other standard forms used with physicians?” asked Beth.

“Yes,” replied Maria. “The Health Summary form should be sent to the child’s physician. This document contains important information concerning the child’s birth history and any developmental issues identified by the physician. This form is important because the medical information can be used for eligibility determination, but any developmental information can also be used to help prepare for the initial assessment and to plan for the initial IFSP.”

“What if a child is referred and has not had a medical health screening or well-baby check-up recently?” asked Beth.

“This might occur if the family has recently moved to the area or has lost touch with their primary physician. The Service Coordinator or service provider can assist them in finding a primary physician. We should encourage the family and help them obtain an appropriate screening for their child from a local physician or the local health department.”

“Okay, the newborn and medical conditions seem fairly straightforward to me,” said Beth. “Basically, the Service Coordinator gets confirmation of the child’s condition and developmental status from physicians’ or hospital records and then uses that information to determine the child is eligible.” Maria nodded.

Beth stopped to reflect on the list of medical conditions listed on the eligibility criteria and she briefly reviewed the health summary form. Next she will tackle a review of the criteria as it relates to developmental delay.

A FAMILY’S STORY

Sam and Katherine Stewart are the new parents of twins, Jessica and Jackie. They have just learned that Jackie has Down syndrome. The hospital social worker is explaining the First Steps program to the new parents.

A Family's Story – “The Stewarts

Sam and Katherine Stewart couldn't imagine what went wrong. They were happily awaiting the birth of twins when Katherine went into labor 34 weeks into her pregnancy. Katherine's OB-GYN, Dr. Haltom, assured her that the babies were “far enough along” and there should be no complications. Katherine was taken to the delivery room accompanied by her husband, Sam. After several hard contractions and a few pushes, Jessica was born. She had a hearty cry and everyone in the delivery room congratulated Katherine and Sam on the delivery of a beautiful baby girl. As Jessica was whisked away to be weighed and measured, Jackie was delivered. However, there was no cry.

There were no “congratulations.” As the nurse hurried away with Jackie in her arms, Katherine became alarmed. As she watched Jackie being taken away, she noticed Jackie was not pink like Jessica. She was somewhat blue. “What's wrong? Where are you taking my baby?” Dr. Haltom told her there may be some problems and as soon as she knew something, she would talk to Sam and Katherine.

Two hours later, Dr. Haltom, came into Katherine's room where she and Sam anxiously awaited news about Jackie. Jessica seemed to be doing well. She weighed 5 ½ pounds and had APGAR scores of 7 and 9. However, since she was four weeks premature, she was in the Neonatal Intensive Care Unit (NICU) for observation. As Dr. Haltom entered the room, Sam and Katherine noticed she was accompanied by someone else. Dr. Haltom introduced them to Dr. Taylor, the neonatologist. Sam and Katherine could not hide their worry and concern. Dr. Taylor looked at both of them and said, “It appears your baby has a condition called Down syndrome.”

Katherine burst into tears. “How can that be? I did everything right. I didn't smoke or drink. I ate only good foods. You must be mistaken.” Sam held his wife's hand, looked at Dr. Taylor and said, “What do we need to do?” Dr. Haltom told them they needed to get the necessary tests to confirm Jackie had Down syndrome. In the meantime, he would like to send a Social Worker to the room to discuss some options with them. With tears still in her eyes, Katherine nodded.

Three hours passed. When Tara Jackson entered Katherine's room, she shook hands with Katherine and Sam and introduced herself as a hospital social worker. “I understand you just gave birth to twin girls. Congratulations.”

“Thank you” Sam replied with a weak smile. “I'm afraid my wife and I are still in a state of shock. They said one of the babies, Jackie, has Down syndrome. We don't know what to do.”

Tara answered, “There is a program available for infants and toddlers with developmental delays.” She briefly explained the First Steps program to Sam and Katherine. She told them once a referral was made, a Service Coordinator would contact them. It was their choice whether or not to participate in the program, but the hospital would complete the initial paperwork and they would still have time to think about what they wanted to do.

Although Tara did not need the Stewart's permission to make the referral, she understood it would be better to let them know so they would not be surprised by the Service Coordinator's phone call.

"Hi, Ellen. This is Tara Jackson at Memorial Hospital. I have a referral for you."

"Hi Tara," said Ellen, Service Coordinator. "Let me get a referral form and take down the necessary information for the early intervention record. Okay, what can you tell me?" Tara proceeded to relay information regarding baby Jackie and her parents. Tara told Ellen it appeared Jackie was born with Down syndrome and that she had a twin sister. Her sister, Jessica, appeared to be fine. Both were born prematurely at 34 weeks gestation, but Jessica weighed 5 1/2 pounds with an APGAR of 9. She was in the NICU for observation, but the prognosis was good. However, Jackie had some difficulty at birth with an APGAR of 5. "How much did Jackie weigh?" asked Ellen.

"She weighed 5 pounds", said Tara. "Although she is small, she does not fall into the very low birth weight (VLBW) category."

Ellen wanted to know about Jackie's parents. "How are they handling the news?"

Tara replied, "Well, about as good as can be expected, when you receive the news that your baby may have problems. I don't think the reality has set in yet. I think they are still in shock. I told them I would be contacting you to make a referral to the First Steps program." Tara gave Ellen the demographic information about the Stewarts including Sam's cell phone number.

Ellen wrote down the information and said, "If Jackie does have Down syndrome, she has a diagnosed condition that would make her eligible for First Steps. I'll need the medical documentation, but I won't need to complete a developmental test. I'll contact the parents and see if they are willing to talk to me right now. If not, I'll try to set up something later, when they've had time to adjust."

After Ellen finished the call with Tara, she called Sam Stewart. Ellen identified herself and explained that Tara Jackson, the hospital Social Worker, contacted her about his daughter, Jackie. "I understand this is a difficult time for you right now, but I would like to sit down with you and your wife to discuss the First Steps program and how we can help your family."

Sam replied, "I think we need as much help as we can get right now, but let me talk to my wife to see how she feels about discussing this with someone outside of the family. If you give me your phone number, I will call you back," Sam replied. Ellen gave Sam the number.

The next morning Sam called Ellen. When he spoke he sounded tired. "The doctors talked to us this morning. The medical tests confirm that Jackie does have Down

syndrome. Katherine can't stop crying, but agrees we need to start thinking about help for Jackie. We would like to talk to you."

"I will be happy to talk with you and your wife. When would be a good time for the two of you?" Ellen asked.

"Well, Katherine and baby Jessica are being released from the hospital tomorrow. I think Katherine is going to need a few days before she's ready. She hasn't slept and bringing a newborn home will add to the stress she already feels leaving Jackie in the NICU," responded Sam.

"I understand completely," responded Ellen. "Take your time and call me when you and Katherine are ready to talk more about First Steps."

Four days later Katherine called Ellen. "I would like to meet with you and talk about this First Steps program. Can you still meet with us?" she asked.

"Absolutely," replied Ellen. "When and where would be convenient for you?" she asked.

"Right now, I'm trying to spend as much time as possible with Jackie in the NICU and breastfeed Jessica. I was hoping we could meet tomorrow at the hospital. My mother will watch Jessica, so you can talk to me and Sam. Will that be okay?"

Ellen immediately said, "Of course, that's fine with me. What time works for all of you?" Katherine responded that noon would work best. "Sam can use his lunch break and we can all meet in the hospital coffee shop." "That's great," replied Ellen. "I will see you and Sam tomorrow in the hospital coffee shop at noon."

Ellen arrived at the hospital coffee shop at noon. She looked around and saw two women and a man sitting at table. The younger of the two women was holding a baby. Ellen approached the table and asked if they were the Stewarts. The man stood up and said, "Yes, I'm Sam. This is my wife Katherine; my mother-in-law, Barb; and our little Jessica." He extended his hand.

Ellen shook his hand and said, "I'm Ellen. I am a Service Coordinator from First Steps. It is very nice to meet all of you. My, Jessica is a beautiful baby. Congratulations on the birth of your daughters."

Katherine smiled and said, "Please sit down. I've just finished feeding Jessica and my mother is going to take a walk with her while we talk." Barb took Jessica from Katherine and walked out of the coffee shop.

Ellen began the discussion. "I know this has been quite a shock for you and, if you are ready, I will be happy to explain the First Steps program to you."

Katherine looked at Sam and nodded to Ellen. “Yes, I think we’re ready.” Ellen explained the First Steps program to Sam and Katherine. She talked them through the process step-by-step, beginning with intake, moving through eligibility, assessment, and IFSP development. She emphasized the fact that as Jackie’s parents, they are a very important part of the team. Ellen also provided them with a brochure explaining the process and the types of services available to them if needed. She asked if they had any questions.

“Is this something we have to do?” asked Sam.

“No, participating in the First Steps program is voluntary on your part,” Ellen responded. “If you choose not to participate, that is your choice,” she continued. Katherine was concerned about the expense. “Although we have insurance, the hospital bills for Jackie will still be sizeable. How much is this going to cost?” asked Katherine.

Ellen explained the System of Payments for Family Cost Participation and insurance mandates in the First Steps program. Katherine was surprised to learn that her family size and income would put their participation fee at a minimal monthly amount.

“What services will we receive?” asked Katherine.

“That will depend on what your Individualized Family Service Plan (IFSP) team decides. Since you are a part of the team, you will help make the final decision about how we work with you and Jackie. The team may determine that help from a Speech-Language Pathologist or a Physical Therapist is needed.”

Katherine and Sam looked at each other. “Can we talk about this for a minute alone?” asked Sam. “Of course,” replied Ellen. “I’ll just get a cup of coffee and let the two of you talk this over. Just let me know when you’re ready.”

After about ten minutes, Sam approached Ellen. “I think we’re ready,” he said. Ellen returned to the table with Sam. “We would like to proceed,” responded Katherine.

Ellen smiled and said, “Great. I need to gather some information to determine Jackie’s eligibility. First, I need you to sign the consent form for the evaluation of your child. By signing this form, you are giving consent for us to determine that your child is eligible for First Steps.” Sam and Katherine nod.

Sam signs the form. “Now we will need to get a copy of the medical report which states she has Down syndrome,” explained Ellen. “In order to do that, I need you to sign a Release of Information which allows First Steps to contact the hospital and doctors asking them to provide us with copies of her medical records. Once we have the necessary documentation, we can determine Jackie’s eligibility.”

“Yes, of course we will be happy to sign the release,” said Sam. Ellen took the necessary forms from her briefcase. She showed the forms to the Stewarts and discussed the content with them. “If you are ready, you can sign the forms and I can begin collecting

information,” said Ellen. “Once I receive the documentation, we can begin to figure out what we need to do before the initial IFSP meeting. I will let you know as soon as I hear from the hospital and Jackie’s doctors.” Katherine’s eyes began to well with tears. “We can’t thank you enough for meeting with us. We really had no idea what we were going to do. At least we have some hope that there are supports and resources that can help us.”

Ellen left the Stewarts and returned to the First Steps SPOE office. She faxed the signed Release of Information to the hospital and to Jackie’s doctors requesting the medical documentation be faxed to her office at the SPOE. She documented all of the information in Jackie’s electronic record, including information from the Stewarts, the release of medical information form, and the date the documents were faxed to the hospital and doctors.

Three days later, Ellen received a fax from the hospital’s geneticist, Dr. Hu. The fax contained medical documentation that Jackie’s tests confirmed she had a diagnosis of Down syndrome. Ellen was ready to determine eligibility and then plan for the IFSP meeting. Later that day, a fax came in from Jackie’s neonatologist, Dr. Taylor. Ellen was pleased to see that each of the five developmental domains was addressed in Dr. Taylor’s report. Ellen now had developmental status in each domain to help with the initial assessment.

Ellen called Katherine and told her the medical documentation confirmed that Jackie had a diagnosis of Down syndrome. Since Down syndrome is a genetic condition listed in the First Steps eligibility criteria, Jackie was eligible for First Steps. Katherine thanked Ellen for calling.

“What do we do now?” asked Katherine. “Now we proceed to the next stage, assessment. This is an important step to help us develop for your family’s service plan. We’ll need to identify a First Steps provider to complete the initial assessment. Based on my conversation with you and Dr. Taylor’s report, it looks like the main concerns are motor development or activities related to the physical domain. I will gather some information about providers who can help in this area and I will call you back later today.”

After she hung up, Ellen completed the eligibility section in Jackie’s electronic record.

REFLECTIVE QUESTIONS

Think about the following questions as you reflect on the newborn/medical information in this section of the course:

1. Think about the 45-day timeline for holding the initial IFSP meeting. What are the reasons for such a timeline? Can the timeline be extended, and if so, why?
2. Reflect back on the eligibility criteria for newborn and medical conditions. Do you remember the criteria for very low birth weight? Are you familiar with all the genetic conditions and additional medical conditions known to be associated with

development disabilities? Will you need to do an evaluation to determine eligibility criteria for these children? What additional information must be documented for these children before eligibility determination?

3. Think about the role of informed clinical opinion in determining eligibility.
 - Who can provide informed clinical opinion to be used in eligibility determination?
 - When is it appropriate to use informed clinical opinion?

Module 2 Tab 3: Developmental Delay

In Missouri's First Steps system, developmental delay, as measured by appropriate diagnostic measures and procedures emphasizing the use of informed clinical opinion, is defined as a child who is functioning at half the developmental level that would be expected for a child developing within normal limits and of equal age. The phrase "as measured by appropriate diagnostic measures and procedures including the use of informed clinical opinion" is important, as there may be situations in which a child's development is highly unusual or atypical and not easily captured by checklists and evaluation tools. In these situations, test scores must be compared to other pieces of information, such as parent report and observation, to see if they are compatible. In the case of infants born prematurely, the adjusted chronological age (which is calculated by deducting one-half of the prematurity from the child's chronological age) should be assigned for a period of up to 12 months or longer if recommended by the child's physician. The delay must be identified in one or more of the following areas:

- a. cognitive development
- b. communication development
- c. adaptive development
- d. physical development, including vision and hearing
- e. social or emotional development.

When determining eligibility for a child with a suspected developmental delay, the Service Coordinator will use the Developmental Assessment of Young Children – Second Edition (DAYC-2) results in addition to the other information gathered to make an eligibility determination. In some cases, the results of the DAYC-2 will clearly confirm eligibility based on at least a half age delay, yet it is very important to understand that no single procedure is used as the sole criterion for determining a child's eligibility.

Therefore a test score cannot be the only determining factor for eligibility. A test score is simply one piece of information that should be looked at in combination with all of the other information that has been gathered about the child. In a situation where only one discipline conducted an evaluation and no medical information related to development is available, the Service Coordinator may be considered the second discipline/profession in the multidisciplinary evaluation. This is due to their role in the evaluation process reviewing and integrating the available information gathered from screening, physicians, parents, and others conducting evaluations/assessments.

What Does the IDEA Say?

According to Part C of IDEA, the multidisciplinary evaluation of the child must include the following:

1. administering an evaluation instrument
2. a review of medical, educational or other records
3. taking the child's history (including interviewing the parent)
4. an evaluation of the child's level of functioning in each of the following areas:
 - cognitive development
 - physical development, including vision and hearing
 - communication development
 - social/emotional development and
 - adaptive development
5. Gathering information from other sources such as family members, other caregivers, medical providers, social workers, and educators, if necessary, to understand the full scope of the child's unique strengths and needs.

It is very important to understand that no single procedure is used as the sole criterion for determining a child's eligibility.

Atypical development refers to behavior or functioning that is abnormal for children without disabilities who are the same age, such as echolalia, self-abusive behaviors, significant sensory issues, or a child who has a significant delay in receptive language abilities but appears age appropriate in expressive language. Some children may exhibit atypical development that is significant enough to contribute to an eligibility determination based on informed clinical opinion.

To be considered for ICO, atypical development must be present in one of these four areas: behaviors and skills not easily captured by instruments, lack of progress, regression of skills, or significance of delay when considering other factors. While test results may not confirm a half age delay, the review of all available documentation supports the conclusion that the child is truly experiencing delays equivalent to that level.

During the evaluation, the provider has the opportunity to observe the child and discuss any concerns the family may have with the child's development. If the provider observes any atypical development or other unique concerns, then the provider must document the observations in the written report. The provider's report must detail any concerns regarding the child's development and must synthesize all information collected through formal (e.g., an instrument) and informal (e.g., observations) methods. The provider's use of the phrase "in my informed clinical opinion" is not sufficient for the Service Coordinator to consider ICO, unless atypical development is identified.

When concerns regarding atypical development arise, the provider and the Service Coordinator must discuss the unique circumstances. In addition to observations and a written report, the Service Coordinator reviews information from the individuals involved in the evaluation of the child to build a rationale for ICO.

Documentation must be thorough enough to clearly support the decision to use informed clinical opinion as the basis for eligibility determination. However, it is not appropriate to

use this rationale for children who show general scatter in developmental domains or who have global delays that are not at the level of half age delay in any domain.

BETH'S STORY

“I was looking on the website and saw information about a test called the DAYC. Is that used for all of the children?” asked Beth.

“No, not all children will receive an evaluation,” responded Maria. “The DAYC-2 is used as the uniform instrument to test all children who are referred for developmental delay. In First Steps, a provider has to complete specific training in order to be paid as a provider who conducts the DAYC-2 to assist with eligibility determination, so it isn't something that every provider does. But, from what I've heard, both parents and providers like it.”

Developmental Assessment of Young Children - Second Edition

The DAYC-2 is a norm-referenced evaluation tool that uses professional observation and caregiver report. It consists of five subtests that measure developmental abilities in the following areas: cognition, communication, social-emotional development, physical development and adaptive (self-help) skills.

The DAYC-2 can be administered by a single service provider for all domains to determine eligibility (e.g., a speech therapist can assess all five domains, not just the communication domain). It is designed for children from birth through 5 years 11 months of age. The DAYC-2 is completed through observation in the child's natural setting, combined with interviews with the primary caregivers for skills not observed.

“How do you know if a child is eligible based on a developmental delay?” asked Beth.

“When I looked at the federal law, I thought it said that children who were at-risk could be served.”

Maria thought a minute. “Each state gets to set the specific criteria. Though the law does allow states to serve children who are at-risk, Missouri does not serve children at risk for developmental delays. When we have families where children are at-risk, we make sure they know the resources and supports that are available in the community.”

“So, the DAYC-2 is the only standardized assessment that would ever be used for eligibility determination?” asked Beth.

“No, not necessarily; the SPOE may request additional tests in addition to the DAYC-2 or sometimes the provider who is doing the evaluation may decide that an additional instrument is needed. In fact, First Steps does not have specific standardized test requirements beyond using the DAYC-2. If additional information is needed, the additional tools can be either norm-referenced, criterion-referenced, or informal, such as observation of the child at play.”

“It’s been a while since I studied about norm-referenced and criterion-referenced tests. Would you mind giving me a brief review?” asked Beth.

“Sure, norm-referenced tests like the DAYC-2 compare scores of the child taking the test to the performance of peers who have taken this same test. These types of tests allow us to compare one child’s performance to his or her peers to determine if the child’s development is on target, delayed, or advanced. Norm-referenced tests are usually used for screening and eligibility determination but they aren’t good for documenting growth.”

Beth nodded.

“In a criterion-referenced test, the scores for the child are compared to a set criterion or standard. The goal of these types of tests is to determine if the child has mastered a specific skill. Criterion-referenced tools are good for documenting growth and compare the child’s current performance to an earlier performance.”

Beth said, “Okay, that helps.”

“Good!” exclaimed Maria. “I’ll signal the waiter for the check and then we’ll finish up with eligibility determination.”

Maria continued. “Remember earlier when I told you about the criteria for children coming in? The Service Coordinator reviews all existing information from the intake and evaluation process to determine eligibility. This includes screenings conducted outside of First Steps, medical records, parent reports, observations, standardized test results and assessments. The review can be done without a team meeting unless the Service Coordinator needs more input in considering all of the data and reaching a conclusion.”

“Wait, I thought just the medical record or the DAYC -2 results would tell the Service Coordinator if the child qualifies or not. Is there something else?” asked Beth.

“There must be more than just one piece of information,” explained Maria. “The federal requirements tell us no single procedure is used as the sole criterion for determining a child’s eligibility. So the eligibility decision is not based solely on the results of the DAYC-2, but also takes into account other information.”

“Do you remember there are two ways for children to enter the system?” asked Maria.

Beth nodded and replied, “Yes. Children come in with either a newborn/medical condition or as having a developmental delay. So children who come in with a newborn/medical condition do not need to be evaluated with the DAYC-2.”

“You got it!” exclaimed Maria. “It’s the children who have a developmental delay who are evaluated using the DAYC-2.”

“But what if the test results don’t show exactly a half-age delay?” asked Beth.

“The criteria for eligibility is half-age development in at least one domain, which is based on the DAYC-2, but it also must include additional observations, parent report, informal measures and any other information that was collected. But there are children who have atypical development and the significance of their delay isn’t clearly captured on a standardized tool like the DAYC-2 or really any other formal test. For these children we consider a process called Informed Clinical Opinion or ICO.”

Maria continued. “An ICO is based on the knowledge and skills of the entire team, including the parents. The sole use of test scores for eligibility determination is insufficient without further interpretation, observations, and information gathered from interviews and other informal assessments. Informed clinical opinion involves synthesizing all of the information gathered about the child. While the test results didn’t show a half age delay, there were atypical things occurring. Maybe it was behaviors that couldn’t be captured by the protocol items. Or maybe it was other factors not related to the testing session but they were significant because it’s impacting the child’s development in a certain area. The review of all available documentation supports the conclusion that although the child’s test scores didn’t show a half age delay, the child is functioning lower than what the test shows.”

“The documentation must be really thorough to clearly support the decision to use ICO for eligibility determination,” Maria said. You can’t use it for children who show general scatter in developmental domains or who have global delays that are not at the level of half age delay in any domain. It isn’t a way to get around the eligibility criteria, but a way to show that the child meets the criteria.”

“I want to make sure that you realize not all children referred to First Steps are going to be found eligible for the program,” said Maria.

Beth nodded.

“Every situation needs to be individually considered before any evaluations are planned or conducted,” continued Maria. “The Service Coordinator uses the information collected through the intake process to describe the child’s developmental status and diagnosis, if one exists, in order to determine eligibility. If eligibility can’t be determined from the information collected, the Service Coordinator needs to conduct additional activities for eligibility determination.”

“If the child is determined ineligible, the family is informed through a letter and a ‘Notice of Action of Ineligibility.’ This notice and the accompanying parent rights document let them know that they have the right to file a complaint if they do not agree with the determination of ineligibility. “

“Is there anything else that the family receives if their child is not eligible?” asked Beth.

“The Service Coordinator should also provide the family with information about other community resources and/or services that may benefit the family,” said Maria. “The family is reminded they can make another referral to First Steps in the future, if they believe their child’s continued lack of development might qualify them for First Steps services at any time.”

“What happens next, when the child is eligible for services?” asked Beth.

“If the child is eligible, the Service Coordinator completes the required steps for documenting eligibility determination including the area(s) in which the child was found to be delayed and the degree of delay. Once the child is determined eligible, the Service Coordinator continues with the family to facilitate the next steps toward planning and preparing for the development of the IFSP.”

Maria concluded, “Developing the IFSP is another process. Let’s talk about that another time.”

As Beth left, she had a lot to think about, but she was intrigued. She looked forward to the day that she would be a competent and confident provider for families and children in First Steps.

“Let’s do this again soon,” Beth called to Maria as they walked to their cars.

A PROVIDER’S STORY

Cathy, a Speech Language Pathologist and First Steps provider, reflects on the process of eligibility determination, use of informed clinical opinion, and the challenges of report writing.

Cathy is a Speech-Language Pathologist who works part-time for First Steps. While she drove to her next appointment, she thought about eligibility determination. The process for determining eligibility was not that different from how she was trained, although more emphasis was placed on parent report, concerns, and their perception of the child’s performance.

Before administering the DAYC-2, Cathy reviewed the handouts and notes she received at the state training. Having one process for all children who enter into the system with a developmental delay did help ensure that the same information was being collected on all of the children. Cathy knew using the same process across the state would help Service Coordinators make eligibility decisions in a similar manner. But she was glad that there was still the Informed Clinical Opinion process, particularly for children whose challenges were not easily addressed by typical assessment tools.

Just recently, she evaluated a little boy, Mark, who didn’t quite meet criteria on the DAYC-2. Yet, Mark had been kicked out of two childcare centers because of his aggressive behavior, severe temper tantrums, head banging, rigid food preferences, and a

need to have everything be the same. During the testing session, Mark did quite well, but both his parents and childcare providers described him as being extremely challenging with hours of screaming on many days. In addition to herself, an Occupational Therapist and a Special Instructor completed some observations and other informal measures. Fortunately, the Special Instructor was also trained as an ABA program consultant and used a standardized measure that utilized both parent and teacher report. Based on input from the whole team and through the use of ICO, Mark was found eligible for First Steps.

Sometimes Cathy needed to remind herself that ICO wasn't to be used to get around the eligibility criteria, but to provide another way of documenting the delays and challenges of the child other than just what the test protocol shows. Targeting skills in the families' routines and daily activities made total sense to her, so it wasn't hard to make that switch from a more medical model to the Part C model. She had been able to accompany a provider on a number of visits and see the system in action, which helped a lot. It was so exciting for Cathy to see the changes in families and children and to know that she was doing something that could make an enormous difference for them.

Although Cathy enjoyed the testing part of the job, she still struggled with writing reports using family friendly language. Learning to write reports for families and other providers in First Steps was much harder than writing clinical reports. Cathy found that the formal medical language she learned to use in her training program prevailed and she struggled to write in family friendly language. Cathy also knew, from reading reports by other providers, it was easier for her to understand the reports from the Occupational Therapist or Physical Therapist on the team if they were written in family friendly language. Just like many parents, she didn't know all of their professional terms *and* acronyms either.

Cathy sat down and attempted to write an initial report for a child she recently evaluated, Julio, using the DAYC-2 reporting form. She liked having the results of the test and all of her observations in one place. The last time Cathy wrote a report, she knew it hadn't been very good. She tried to rewrite it, but finally gave up and just turned it in. When she told the Service Coordinator, Charlie, that she was really struggling with this, Charlie volunteered to help. "Since you have the data for Julio, go ahead and write it up, and then let's meet. We can discuss the report together. I think with a little practice this will become much easier for you."

Although she was a little embarrassed about it, Cathy decided she would meet with Charlie. First, she scored Julio's test. Then, using the protocol and her notes, Cathy wrote her report. She decided that she'd do it right away and meet with Charlie in the next day or two to review. Cathy read her first draft and thought that it wasn't too bad, but called Charlie to see when they could get together. They scheduled a time for the following day.

Charlie read her report and smiled. "I think you're getting the idea, but this could still use some work. I'm not sure what all of this means and if I don't, Julio's mother and grandparents probably won't either. Let's read it through together and you can explain what you mean to me and then we'll figure out how else you might say it in words that are family-friendly. For example, using the word 'patient' makes him sound sick." Cathy

admitted she had not considered that. “It’s ok to just use his name,” Charlie continued. “Even just changing that will help. Now let’s look at the rest of it.”

“Ok, now we’ve reviewed.” said Charlie. “Are you more comfortable with how to write these reports now?”

Cathy nodded and said, “When I’m trying to decide on what words to use or how to write something up in First Steps I will remember a couple of things. First, I want to focus on what the child can do. If I describe the highest level of skills, it helps clarify what the child isn’t yet doing. For instance, if I write ‘Johnny uses a variety of consonant sounds including b, p, and m.’ It’s pretty obvious that if the child was able to talk, I wouldn’t be talking about vocalizing individual sounds. Second, I want to use the language that is familiar to virtually every adult. I don’t want to write a report that only one group of professionals can read or understand. Third, I want to make sure that the report includes information related to the concerns of the parent. If the parent’s concern is about behavior, I want to make sure I address the child’s behavior in the report, including the information I gathered from them.

Cathy continued. “Thanks for your help, Charlie. It’s funny that I recognize an informative, easy to read report when I read one, but it’s still pretty hard for me to write one that way. I just keep telling myself that with practice I’ll get better. Anyway, thanks again. I owe you!”

Cathy drove away feeling good about her experience with Julio and his family and that her report would be useful to them. Based on her findings from the DAYC-2 and the rest of the information that was collected, it seemed likely that Julio would meet the eligibility criteria for First Steps. She smiled thinking that Julio’s mother and grandmother would receive help.

Cathy wondered if she’d be the primary provider to serve Julio’s family. Given that his greatest need was in communication, it seemed probable that she’d be the person from her team to take that role. Although Cathy would be happy to be the primary provider for Julio and his family, she also realized that given Julio’s atypical behaviors and sensory issues, the Special Instructor or even the Occupational Therapist would also be good choices for Julio. It would really depend on who the IFSP team decided was the best fit for the family.

Administering the DAYC

This video depicts a First Steps provider administering the Developmental Assessment of Young Children (DAYC) in the child’s natural setting.

REFLECTIVE QUESTIONS

Think about the following questions as you reflect on the developmental delay material in this section of the course:

1. Multidisciplinary evaluation infers gathering information from multiple sources. Can you think of all the information sources that IDEA indicates should be included?
2. IDEA allows states to make the decision whether to serve children at-risk for developmental delays. Missouri does not serve at-risk children in the First Steps Program. How can you as a service provider offer support for families with children at-risk for development delays? What community resources and supports are you familiar with that are available for these children?
3. Norm-referenced tests are used for eligibility determination but not for documenting growth. Think about why you would choose to use a criterion-referenced test for measuring growth. Would you describe the DAYC-2 as a norm-referenced or criterion-referenced test?
4. Part C of IDEA includes 5 components to be included in the multidisciplinary evaluation. Name the five components and at least one activity related to each.
5. Using informed clinical opinion (ICO) in the eligibility process involves synthesizing the information gathered about a child. Think about who is involved and what information is considered when making an ICO. Under what circumstances might you use ICO to make an eligibility determination? When is it inappropriate to use ICO?

Module 2 Tab 4: Screening & Evaluating

Screening is defined a "snapshot" of the child's development at a particular point in time. The purpose of screening is to determine whether to refer a child to Part C. The First Steps program does not conduct screenings in order to assist with eligibility determination; therefore, First Steps encourages referral sources, such as Parents as Teachers or physicians, to have screening results sent to First Steps when making a referral. The Service Coordinator uses the screening in conjunction with other information, including the reason for referral, parent interview, existing medical information, to determine whether a child is eligible for First Steps.

Evaluation is defined as the use of informal and formal procedures to determine whether a child is eligible for First Steps due to a developmental delay. The purpose of an evaluation is to establish a developmental age or degree of delay to assist with eligibility determination. Federal and state regulations require a timely, comprehensive, multidisciplinary evaluation of each child, birth up to age three referred for evaluation.

Multidisciplinary means the involvement of two or more separate disciplines or professions in the provision of integrated and coordinated services, including evaluation and assessment activities. Prior notice and written consent must be obtained from the parent for any and all evaluation and assessment activities. Service Coordinators are responsible for ensuring that the family understands the intent and purpose of any evaluation and assessment activity.

Evaluation of each child must be conducted by personnel trained to utilize appropriate methods and procedures, be based on informed clinical opinion, and include a review of the pertinent records related to the child's current health status and medical history.

Developmental Domains

The child's level of functioning must be addressed for each of the following developmental areas:

1. Cognitive Development
2. Physical Development including vision and hearing
3. Communication Development
4. Social/Emotional Development
5. Adaptive Development

In conjunction with an evaluation, an assessment of the unique needs of the child may be completed for each developmental areas listed above in order to identify the services appropriate to meet those needs.

Considerations When Screening or Evaluating

1. Be sensitive and pay attention to parental concerns
2. Provide thoughtful inquiry about parental observations
3. Conduct observations that include a wide variety of the child's behaviors
4. Review developmental milestones through a checklist or protocol, if applicable
5. Use all encounters with the child as opportunity for observing and recording developmental status
6. Include screening of vision and hearing to rule out sensory impairment as a cause of the delay
7. Be sure to note any observations of parent-child interactions during the screening or evaluation.

BETH'S STORY

The week following her discussion at lunch with Maria, left Beth wondering about how screening and evaluation relate to the process of eligibility determination. Beth picked up the phone and called Maria.

"Hi Maria, I am still wondering about the distinction between screening and evaluation. Do you have time to chat?" asked Beth.

"I have an appointment at 1:30, but I can chat for a minute," said Maria. "It can get a bit overwhelming to try and take in a lot of information at once. I'm glad you are continuing to think about First Steps and how eligibility determination works."

"It's hard for me to keep things straight," said Beth. "I keep thinking about how hard it must be for families, who are also grappling with the idea that their baby has a disability. I'll bet many of them need to hear things more than once – I know I do."

"Yes, I agree," replied Maria. "Tell me what is bothering you."

"In my old practice, we had to use a screening tool when we gathered that initial information," said Beth. "Is that how you think about screening? Is it a specific test or tool?"

"In First Steps, we think of screening more broadly than just one instrument or observation of the child," responded Maria. "Sometimes parents have a form that has been done by a physician or someone else and we consider that as screening information. But other times we receive notes about an observation or visit with the child that has been done by Parents as Teachers and concerns were noted about the child's development. "

Maria continued, "Screenings are usually performed as a one-time procedure designed to identify young children considered at-risk or children who will possibly need services to help their development. Sometimes professionals have multiple notes or visits by the time they refer the child to First Steps. It helps me to remember what the purpose of screening is if I can answer these questions: 'Is the child on-track for his/her development?' 'Am I concerned about the child's development?' 'Does the child need further evaluation?'

“Who conducts a screening?” asked Beth.

“Typically, a screening has been completed at the time that a child is referred to First Steps for developmental delays or concerns,” said Maria. “These results can be obtained, with parental permission, by sources such as the child’s physician or a Parent as Teachers educator.”

Beth thought for a minute. “What happens after the screening? It seems like sometimes the screening will show that the child is eligible and other times not.”

Maria clarified, “Try not to get confused about the types of instruments used for screening and others that are used for evaluation to determine eligibility. Many screening tools do not give scores or percentages that can tell us exactly where the child is performing. Since the First Steps criteria specifies half-age delay, we want to use instruments that can provide us some sort of standardized score so we can determine whether the child is half-age.”

Maria explained, “Once intake is completed and the family has given consent to evaluate, a provider will be selected to complete the evaluation. The Service Coordinator assigned to the family will help assist the family in locating the evaluator from the matrix or from the early intervention team, and setting up the time and location for the test.”

“Does the evaluator get any information on the child and family before completing the evaluation?” asked Beth.

“Yes,” answered Maria. “The Service Coordinator can have a conversation with the provider prior to the evaluation sharing basic information and the child/families areas of concerns with the provider. The Service Coordinator also follows the conversation with a provider service request form that shares that same information. This request form is generated from the child’s electronic record when the Service Coordinator completes the DAYC Request or the Initial Assessment Request.”

“Wow, there is a lot to absorb, but I think I am beginning to see the flow of the referral, intake and eligibility determination process”, said Beth. “Thanks for taking time out of your busy schedule to explain these processes to me. I appreciate it.”

“No problem,” said Maria. “I am happy to help.”

A FAMILY’S STORY

Ellen, a First Steps service coordinator, visits the Martinez family to begin the First Steps referral process by conducting an intake meeting.

Juan’s family is worried his behaviors are getting worse. The Service Coordinator just received a referral for Juan.

A Family Story - The Martinez Family

Ellen, the Service Coordinator, received a call from Mrs. Martinez about her 20 month old grandson, Juan, who she wanted to refer to First Steps. Ellen explained Juan's parent needed to make the referral to First Steps.

Ellen asked if a parent was available and Mrs. Martinez put her daughter, Angela, on the telephone to discuss her son's development. Angela explained she was worried about her son's behaviors, especially at daycare. Juan is almost two years old but he doesn't want to play with other kids and he gets so mad so quickly she is worried he might get hurt. Juan's daycare teacher met with Angela last week and told her that his behaviors are getting worse; he recently started banging his head when he is upset. A few minutes into the conversation about Juan's development, Angela said abruptly, "Sorry, I have to go. Can we schedule another time to talk?"

Ellen set up a visit with Angela for the following week and she asked if her mother, Mrs. Martinez, could be there too.

"Sure," Ellen said. "You can invite anyone you would like to have there to talk about Juan's development."

"Ok that's great," Angela replied. "I am 17 and still living at home, so my mom helps out a lot."

One week later, Ellen arrived at the Martinez home. Ellen brought the forms that she'd filled out when the initial call came in. The intake meeting was with Angela and Mrs. Martinez. Although some information was gathered over the phone, this would be the first chance to really hear Angela talk about her concerns. The apartment was small, but except for toys and blocks on the floor, very neat. Mrs. Martinez greeted her with a worried smile. "I'm so glad you could come. I'm worried about my grandson. I raised three children and none of them were like him. I don't understand and I don't know what to do." In a quieter voice she said, "I know my daughter's young, but she's a good mother and she loves Juan. I just want to help."

She then called to Angela and asked her to come and bring Juan. Angela soon appeared carrying Juan, but didn't make eye contact with her mother or Ellen. Juan wiggled immediately to get down and began to stack blocks. He ignored all the adults and was absorbed in his activity. It was clear that stacking blocks was something he liked to do, and for a child his age, he seemed to do it well.

Angela still hadn't made eye contact and Ellen wondered how she was feeling. After a quick introduction, Ellen usually started the intake meeting by explaining more about First Steps, the goals of the program, and the role of the parents and other caregivers.

"Let me explain how the First Steps program works." Ellen stressed the program philosophy and the importance of Angela and her family in Juan's life. She told them how First Steps would help them support Juan to get along better with other children. She

explained that First Steps was family-centered and that Angela's concerns for her son were important and would be the focus of the program. Ellen also explained family-centered meant that Angela could have other people included in this process – her parents, Marco, or anyone else she wanted to include. However, that would be up to Angela. Ellen also let them know that if he qualified, service providers could work with the daycare, as well as with the family to help Juan participate more fully and appropriately both at home and in his childcare setting. Angela asked how she would be able to get services for Juan.

Ellen explained the eligibility criteria, especially the requirement for a half-age in one developmental area.

“To qualify for services based on developmental delay, we would need to test Juan in all developmental areas and find out where he's at developmentally.” Ellen continued, “If he is at a half-age delay in any area, then he would qualify for services.”

Angela hurriedly said, “Oh yes, I want him to be evaluated. I want someone to help him. He's getting bigger and he needs to learn to talk.” Mrs. Martinez nodded and smiled in agreement.

Angela continued, “I'd like to know where he is at. One of the ladies at the daycare did some sort of test a few weeks ago and told me last week in the meeting that Juan was delayed in several areas. That's why they told me to call First Steps.”

“Ok,” Ellen said. “I think the next step is to get your permission to test Juan in all areas and see where he is at for his age. I would also like to get your permission to talk to the daycare and find out more about their test. Before I can do these things, I need you sign a few forms.”

Angela signed the consent form for the evaluation and a release of information for the preschool.

Next, Ellen wanted to hear more about what Angela was thinking and feeling about Juan and his development. She thought she could take notes and ask specific questions if something wasn't covered.

“Angela, as Juan's mom, you're the most important person in this process. Will you tell me about your son? What does he do well and what are you concerned about?”

Angela looked at her mother and in a quiet voice started to talk about her son. “Juan was a good baby and is a good boy. He just gets mad sometimes and he doesn't know what to do. He is ‘all boy’ and can climb, run, and jump as well as some of the older kids. He runs around a lot. Marco, Juan's father, says he was like that when he was little too. But he doesn't just run around all of the time. He also can sit for a long time and work puzzles, stack blocks, or play with his toy cars. It seems like he just doesn't want to talk and he doesn't want to listen. He's not interested in what I want him to do – or what the

daycare teachers want him to do. I don't know if he can't listen or if he doesn't want to. But, I do know, that when you try to make him do something he doesn't want to do, he gets really mad."

"You've talked about him getting mad a couple of times. What kinds of things make him mad? What does he do when he gets mad?" asked Ellen. Just then the tower toppled before Juan was ready to push it over. He screamed and threw himself on the floor and started kicking and banging his head. Angela immediately ran over to help him fix the tower and gently rubbed his back while talking quietly to him.

After about 15 minutes, Juan calmed down and went back to building. When Angela came back to the couch Ellen asked, "What would happen if you didn't help him? Would he ask you for help or come get you?" Angela shook her head. "No, if someone doesn't come quickly, he usually either keeps screaming, banging his head or starts throwing the blocks- sometimes both at the same time. One time he broke one of my mother's vases and another time he got a big lump on his head, so now I just get to him as fast as I can. I'm afraid he'll hurt himself or someone else. I think that's why they don't want him at daycare anymore. They were afraid one of the other children would get hurt or he'd hurt himself. Sometimes, I think he does it just to show that I'm not a good mother."

"It seems like he gets frustrated and angry when he isn't able to make the toys do what he wants. Are there other things that make him mad?" asked Ellen.

Angela nodded. "He also gets really mad if he's working on a puzzle, building a tower, or playing with cars and someone tries to get him to stop, or if one of the children in his class tries to take his toys. He sometimes bites if anyone takes the toys. He'll even bite the teacher if she takes the toys trying to clean up. Then, he screams and cries and does what you just saw. It's really hard for him to calm down once he's so upset, especially at preschool. It's easier to just let him play the way he wants."

"I can see how that could be really hard at childcare with other children, but it must be hard for you here too."

"It is. If he can't go to childcare, I can't go to school. Even though my mom and dad help me, we can't pay for someone to come here to take care of him. I sometimes think if he could talk and would listen, we could explain things to him and then he wouldn't be so mad. But I don't know."

"Does he ever try to talk to you?" asked Ellen.

"Sometimes it seems like he's trying to tell me something, but I can't understand what he's saying. At home, we speak Spanish a lot to him and to each other. At school, they speak English and sometimes we do too, but what he says doesn't sound like Spanish or English. He can say a few words, mama for me, nana for my mom, no, and leche. He really likes milk! But some days, he doesn't say anything at all and other days, he says things no one can understand. He just gets mad that no one understands. Maybe we

should just speak English to him. I don't know. My grandparents only speak Spanish and everyone else in the family speaks both languages. I wanted Juan to do that too."

Since Juan doesn't use very many words, how does he let you know what he wants?" asked Ellen.

"Sometimes he'll pull me by the hand and put my hand on what he needs help with. If he wants to go outside, he'll pull me over to the door and put my hand on the door handle. Sometimes he points at what he wants, but not very often. Since he likes to do the same things over and over, I sometimes just know what he wants. But if it's something different than usual, that's when we have problems." responded Angela.

"That must be frustrating for you," sympathized Ellen,

"It sounds like Juan gets angry for a lot of reasons, but one reason is that he can't make himself understood. We will look at all of the areas of development, but pay particular attention to his language and communication skills, and also how he gets along with other children and adults."

By the end of the meeting, Angela was smiling and Mrs. Martinez looked less worried than before. Ellen explained that she would be contacting her within the next day or two with the name of the provider who would be completing the evaluation for Juan. "The evaluation is typically conducted at home, because that is where Juan and his family are most comfortable," explained Ellen. Angela nodded. "In the meantime, if you have any questions please give me a call," concluded Ellen.

Ellen left feeling good about this family and this little boy, assured that First Steps would be able to help.

After the visit, Ellen sent the release of information to the daycare and received a copy of their screening the next day. The information was very helpful; it indicated Juan was experiencing delays in communication, adaptive and social-emotional areas. Ellen entered a DAYC Request in the electronic web system with information from the daycare screening and her intake visit, and selected Amelia Lopez, Speech-Language Pathologist as the Early Intervention Examiner.

Amelia called the Martinez family a few days later and set up a time to meet. Because Juan did not have a medical diagnosis Amelia would use the DAYC-2 for the evaluation instrument. She also planned to do some informal evaluation of Juan's skills.

Amelia arrived at 6:00 pm the following week, just as the family was getting up from the table.

Amelia noticed that Juan was eating in front of the TV. Mrs. Martinez smiled apologetically.

“We sometimes try to have him eat with us. He gets upset because he doesn’t want to sit down or he doesn’t like the food – even if we don’t make him eat it! He can stay upset for a long time. I didn’t want him upset for you.”

“Thanks, I appreciate that. Are you Angela Martinez?”

“Oh no.” laughed Mrs. Martinez. “I’m too old for another baby. Angela is my daughter. She’ll be out in a minute. Do you want some coffee while we wait?”

“That would be wonderful, thanks so much.” answered Amelia.

Angela heard and brought coffee for her mother and Amelia. She sat at the edge of the couch looking apprehensive.

Amelia explained that she was going to do a test to help determine if Juan was eligible for First Steps services. Amelia explained, “I can’t decide if he qualifies on my own, but I will share my report with Ellen, your Service Coordinator, to help with determining eligibility.”

Amelia described the process. “Some of the time I will ask you questions about Juan’s skills and other times I will ask Juan to do some things. I’ll also want to know if Juan is behaving like he usually does.” Since little children act differently depending on who is there, Amelia wanted to make sure that she got plenty of information from Angela about what was typical for Juan.

Angela said, “It would be easier if you start by asking me questions. Juan’s video will be over soon. If we turn it off now, he’ll get mad and then it will be hard to get him to do anything.”

Amelia responded, “That sounds like a good idea and you sound like a mom who knows her little boy very, very well. Let’s start with parent report, and when his video is over, we can get him to show us what he can do. Based on the information I got from Ellen, it seems like he does a good job of getting around the apartment as well as running, jumping, and climbing stairs.”

“He is too good at all of that,” smiled Angela.

“I understand,” Amelia said. “Ellen also told me that he likes to do puzzles, stack blocks, play with toy cars, and other things he can do with his hands. Let’s start with some activities like those that I think he’ll enjoy, which will get us off to a good start.”

Juan responded well to those activities and like Angela said, he did well. A couple of times he got frustrated when he had to stop one activity and go to the next, but with Angela’s help he didn’t have a major meltdown. Angela was able to answer most of the parent report items and when she couldn’t, Mrs. Martinez could. The three adults worked together to get the most accurate snapshot of Juan’s development. All in all, it went well.

When they finished, the adults were tired and Juan was ready to run and climb. Luckily, Mr. Martinez came home then and took Juan into the bedroom to jump on the bed. Amelia gathered her materials. “It was so nice to meet both of you and Juan. Do you have questions for me about the evaluation? Do you think Juan was like he usually is? Did I get an accurate picture of what he can do?” Angela nodded yes and looked to her mother for verification. Mrs. Martinez nodded too.

“I don’t have any questions right now. What happens next?” asked Angela.

“I’ll get the evaluation scored as soon as I can and send a copy to Ellen. She’ll contact you and let you know if Juan qualifies for First Steps. If he qualifies, we’ll have another meeting to develop the Individualized Family Service Plan. We’ll work together to figure out what kinds of things you want Juan to be able to do and how we can help you, help him, to do them.”

“But what if he doesn’t qualify?” asked Mrs. Martinez.

“If he doesn’t qualify, you’ll still get the evaluation report and it will include some suggestions for you to work on right away. Ellen will help you find what else may be available in your community to help Juan.

I should have the test scored and the report written in a few days. You’ll hear from us soon after that.”

Though Amelia felt that Juan would qualify, she didn’t want to say anything to the Martinez family until the scores were official.

REFLECTIVE QUESTIONS

Think about the following questions as you reflect on the screening and evaluation information in this section of the course:

1. Screening is a “snapshot” of a child’s development. Why is it important to have a screening completed before making a referral to First Steps?
2. Evaluation is defined as the use of informal and formal procedures to determine whether a child is eligible for First Steps due to a developmental delay. How would you explain the definition and purpose of evaluation to parents in language they could understand?
3. There are five developmental domains that must be addressed during the evaluation of a child. Name the five domains. Can you create a mnemonic to help you remember these five domains? (A mnemonic is a memory device. An example is ROY G BIV for the colors of the rainbow: Red, Orange, Yellow, Green, Blue, Indigo, Violet).

Module 2 Tab 5: Resources

All documents, videos and supplemental materials that are linked in the module can be accessed under the Resources tab. The links to these resources were not included in this transcript.

Module 2 Documents.

1. DAYC- 2 Information
2. First Steps Eligibility Criteria
3. First Steps Evaluation /Assessment Flow Chart
4. First Steps Online Referral System
5. First Steps Referral Form
6. Health Summary
7. Notice of Action/Consent
8. Parental Rights Statement
9. Physician Informed Clinical Opinion Form
10. Release of Information

Module 2 Videos.

1. Parent Perspective of Service Coordination
2. Administering the DAYC

Module 2 Supplemental Resources.

1. Early Childhood Technical Assistance (ECTA) Center – Part C Eligibility
2. Early Childhood Technical Assistance (ECTA) Center – Screening
3. First Steps Practice Manual Chapter 3: Referral, Intake and Evaluation
4. Informed Clinical Opinion
5. Suggested Developmental Screening and Assessment Instruments