First Steps
Module 5: Family Engagement

Module 5 Tab 1: Introduction

Module 5: Family Engagement focuses on some of the challenges and related strategies First Steps providers might need to employ when working with families within the context of their daily routines and activities.

These topics are addressed in this module: working with families who have multiple risks, understanding cultural differences and how those might affect parenting and early intervention services, and ethical issues that frequently arise for professionals who conduct home visits.

OBJECTIVES FOR MODULE 5

1. Define the following terms and describe how they relate to the First Steps program:
    - Child Trauma
    - Environmental factors
    - Ethics
    - Mandated
    - Protective factors
    - Resilience
    - Temperament

2. Describe terms related to ethical practices for:
    - Professional boundaries
    - Confidentiality
    - Reporting abuse and neglect

3. Describe the Three E's of trauma.

4. Describe multiple risks

5. Identify three risk factors

6. Identify three reasons families may choose not to participate in services

7. List the six stages in the developmental model of change

8. Describe three values that differ for families from different cultures

INTRODUCTION

Part C of the Individuals with Disabilities Education Act (IDEA) outlines the legal requirements for providing services to infants and toddlers with disabilities and their families. Although the law provides guidance on the aspects of developing and reviewing the child's IFSP, the law does not address many of the practical issues related to working with families and their young children with disabilities. Working with parents and children in their homes requires providers and families to become partners in intervention.

Additionally, the law does not provide guidance on how to form collaborative relationships with families; particularly families who have multiple risks or families who are culturally different from the provider. Working with parents and children in their homes also raises ethical issues that are not addressed in the law. Often there is little guidance about how to address these challenges.

Families with multiple risks are those who have many challenges and few protective factors, which are conditions that decrease the well-being of children and families. One shared risk factor for families in First Steps is having a child with a disability. Families may have risk factors in others areas as well such as living in poverty and may experience high levels of daily stress. Developing collaborative relationships with families who have multiple risks may prove more challenging than developing relationships with families who have fewer risks.

When service providers work with families who are culturally different from them, this presents other challenges. Culture affects virtually every area of daily life; what we eat, how we dress, the language we speak, and how we parent, to name a few. When providers and parents do not share a set of beliefs about parent-professional roles and relationships, parenting practices or the meaning of a disability; then misunderstandings and miscommunications may occur.

When working closely with families, ethical issues arise that are not addressed in the law or in the code of ethics for each of the professional organizations. Providers may be invited to family celebrations, may be asked to help in ways that are outside their professional practice or may have questions about their role and responsibilities related to confidentiality or reporting abuse or neglect. In order to effectively respond to these types of situations it is important to know what the guidelines are for First Steps service coordinators and providers, and to have a way to think about situations that are not specifically addressed.

Typical transition events for children in First Steps include enrolling in First Steps, beginning early intervention services, changing intervention services, and exiting the First Steps system of services. One of the most critical factors affecting transitions in early intervention is the way in which families, providers, and school personnel view transition planning. When transition is viewed as an isolated event that children and families go through, transition is often disjointed and leads to increased anxiety for many of the parties involved. On the other hand, when transition is viewed as a process, the transition experience is much more meaningful and successful for families, service providers, and school districts.

Although transitions are unique experiences for all young children and families, the transition experiences of young children with disabilities can pose significant challenges for the child, the family and professionals (Rous, Hallam, Harbin, McCormick & Jung, 2005). There are some common barriers that more specifically affect the transition process for children with significant disabilities. Several of these barriers relate to a lack of parent involvement and interest.

It is important for people working with families to understand these barriers and provide support for families as they continue to deal with the challenges of raising a child with a disability. Strong support for families when these children are very young is important for laying a strong foundation for these families as their children grow and develop.

BETH'S STORY

(Continued from Modules 1 – 4. Reminder: Beth is a recent graduate who is learning about the First Steps program as she becomes a new First Steps provider.)

Beth and Miko, a physical therapist, arrived in the parking lot at the same time.

"Hi Beth, thanks for including me" said Miko with a smile. "I've been a physical therapist for five years but working in a hospital was really different than what I'm doing now. I love it but I still have a lot to learn. I thought that since my parents moved here when I was four I would have an easy time working with families from other cultures, but that is only sort of true. I also thought that speaking Japanese would be helpful, but my skills haven't been needed very often. Who else is going to be here?" asked Miko. Beth replied. "Maria. You might remember she's a Speech-Language Pathologist who has worked mostly in urban areas. She is fluent in Spanish but her parents are from Spain, unlike most of her Spanish-speaking clients who come from Mexico or Central America. I think that's been challenging for her. People assume that since she speaks Spanish her culture is the same as everyone who speaks Spanish. She's been a practitioner for 2 years."

Beth continued, "The other person who is coming is Tanya. Tanya is a service coordinator who has worked for First Steps for almost 10 years. She has worked in many areas of the state including both rural and urban areas. I got to observe her with a couple of families and she makes it look so easy. I don't know exactly how she does it, but families warm up to her so quickly. I'm hoping she has some tips for me."

"That's why I'm here, too" said Miko.

They sat down at the table and looked up as Maria walked in.

Beth introduced everyone, then Maria addressed Miko. "Glad to meet you. How do you know Beth?"

"Beth and I have been friends for about a year. She's been so excited about becoming a First Steps provider that I decided I should do it too," said Miko with a grin. "I've only been a

provider for six months and I really like it but Beth and I have talked about not knowing how to handle some of the situations that arise."

"I've had that experience, too," said Maria. "I'm really glad we're meeting. Overall, I feel like I've made a difference and have seen many children and families grow and change. But there are some families that I don't feel like I've been able to really help and I'd like to do that better. I jotted down the questions that we said we wanted to talk about. These are issues we have talked about before. They seem to cover two main topics – challenging home visits and ethics."

Just then, Tanya entered. "Hi, sorry I'm a few minutes late. I had an IFSP meeting that ran late. Let's get started."

Maria handed the list of topics to Tanya. "Hi Tanya. Thanks for doing this. I think I emailed this to you but I also brought the list of questions that we all talked about."

Questions to Consider:

- Why is it hard to connect with some families?
- Why do some home visits seem difficult?
- Are there strategies for helping families become more engaged?
- How do we provide services in ways that work for families whose values are different from our own?
- Are there guidelines for making ethical decisions about our relationships with families?

"Thanks for setting this up, Beth," said Tanya. "I'm really glad you invited me to be part of your conversation. I looked at the list and have thought about your questions. There is a lot of overlap in the topics so we won't go through this question-by-question but we will address all of them. Some of these short questions have long answers so we might need to meet a second or even a third time."

Tanya smiled and continued. "I feel like the teacher doing a lecture. I don't want it to be like that so please ask questions and raise other issues. It's fun for me to talk about this stuff. I had many of the same questions when I first started as a service coordinator. I found some useful resources-two books in particular were helpful. I brought them today. A lot of the content about working with a variety of families that I will talk about today comes from these two books."

"I really don't like referring to home visits as challenging because it makes it feel as if the home or the family is the problem, when that's really not the case," explained Tanya. "Let's go back to the resources. One of the books is by Landy and Menna and it is about working with families with multiple risks. It's written from a psychological point of view and some of it isn't directly relevant. But there is a lot that is. The other book is by Lynch and Hanson and is about cross-cultural competence. It's written specifically for people like us who do early intervention in homes with children and families."

“Ok, let’s get started and I guess I am going to play teacher,” said Tanya. “Your first questions are about home visits that you find difficult. In my experience, home visits that I have found challenging, particularly early in my practice, were families with ‘multiple risks’. What does it mean that a family has ‘multiple risks’?

Beth thought for a minute and replied, “I guess it means that they have a lot of things going on that make life hard.”

“It could include things like poverty because poverty makes a lot of things hard, but there are other things as well,” said Miko.

“Right," Tanya responded. “We usually think about the risks being in one of three areas. They could have risks related to child characteristics and that is a risk factor that all families in First Steps have since the reason they get services is because of something going on with their child.”

"The other two areas are parent factors that may negatively affect parent-child interactions and environmental factors. We think about risk factors because, in general, children with more risk factors do worse and children with fewer risk factors tend to do better – but NOT always. And, that's where we come in. The role we play with families and children may help to reduce the effects of the risk factors, even when there are a number of them."

Factors That Put a Child At-Risk for Negative Outcomes

Child characteristics:

- Extremely low birth weight
- Biological and/or genetic conditions
- Chronic health problems
- Difficult temperament

Parent/interactional characteristics:

- Mental illness
- Drug or alcohol abuse
- History of developmental delay
- Criminal history
- Negative experiences as a child
- Other loss or trauma
- Lack of sensitivity or attunement
- Lack of parenting knowledge
- Lack of vocalization and eye contact
- Abuse

Environmental factors:

- Chronic unemployment
- Inadequate income/housing
- Frequent moves and no phone
- Single teen parent
- Violence in the home
- Recent life stresses
- Dangerous neighborhoods
- Education of less than 10 years

Source: Landy, S., & Menna, R. (2006). Early Intervention with Multi-Risk Families (p. 10). Baltimore: Paul H. Brookes Publishing Co.

“That is one of the reasons I wanted to become a First Steps provider,” said Maria. “If we can help families support their child’s development and help build resilience in both the child and the family, we’ve done a lot. But, families who have more risk factors are often hard for me to work with and I feel less effective, even though I know how important it is to be effective.”

A cell phone rang.

"I’m really sorry but I have to get that," said Tanya. “You can take a look at the risk factors while I’m gone. This should only take a minute."

“Families who participate in First Steps have a risk related to child characteristics - they each have a child with a developmental delay or disability,” explained Maria. “Some families may have additional risks related to parent characteristics, like a parent who may experience depression or who has had trauma in his or her life. The last area of risk - environmental factors - includes poverty. Poverty affects many families and many children and makes daily functioning more difficult. As service coordinators and providers, we may find it challenging to provide effective, family-centered services to families living in poverty.”

“Why is it challenging to help families with multiple risks?” asked Miko.

Beth jumped right in with her reply. "I think it is because families with multiple risks often do not participate in home visits but we are not sure why because there are a variety of reasons this may happen, so it is hard for us as providers to figure out how to engage the family and support them in their daily routines."

Maria added to the conversation next by saying, "Something that I have noticed this past year as a provider is that it seems like there are only a few families on my caseload that I would say have multiple risks and I have a hard time connecting with them, but I spend more time trying to find ways to support them and connect with them than I do with some of my other families. It takes up a lot of my time even though the multiple-risk families only account for about 10 percent of my caseload."

"Yes it does take a lot of time," Miko agreed. "Sometimes I want to give up trying, but I have found that when I am able to connect with just one family member in a home visit that was initially challenging, it is so gratifying for me as a provider, to know that I stuck with it and was

It does help to think about the different kinds of risks that families may be experiencing.” said Beth.

Maria nodded. "Some of them are things we know about, like risks related to the child's disability or risks because of poverty, but other things that are about the parent we probably won't know unless they choose to tell us."

"Right," Tanya responded. "I already said that we think about risk factors because usually children and families with more risk factors do worse and children from families with fewer risk

factors do better—but we've all known situations where that wasn't true. Our family-centered system and the way we provide services can help families be resilient."

Beth responded. “Some of the families I work with have lots of risk factors and others don’t. As a First Steps provider I feel really confident about addressing the risks related to the child. That’s what I went to school to learn how to do. But, I didn’t learn nearly as much about working with families, especially families who had multiple risks. A number of the families I work with live in poverty. Since I grew up in a middle class family I sometimes don’t understand what it’s like, and I know that I can be appear to be judgmental.”

Maria and Miko nodded in agreement.

"OK, let's start with poverty," said Tanya. "It's one of the ‘environmental' risk factors we talked about earlier and there are many families and children who are affected by it. What makes poverty such a big risk factor?"

Miko responded first. "Not having enough money affects just about everything; neighborhoods may not be safe, families may not have health care and it's likely that there is only one parent so he or she is responsible for everything, which is stressful. If you're worried about keeping a roof over your head or food on the table and doing that takes many hours a week there may not be time or energy for some of the things we want the parent to do with the child."

Tanya spoke next. "It's important to remember that we're talking in generalities here and that people live in poverty for many different reasons and the effects of poverty are different for different families. Some families who are poor have been poor for generations. Parents may not have a formal education and may have very negative feelings about professionals. They may have had a bad experience when they were children and expect to be criticized and looked down on. They may not appear to be friendly, so building trust may take longer than usual. When you go into their homes, they may not think that there is anything that they can or should do differently for their child."

"That sounds a lot like some of the families that I've worked with," said Beth thoughtfully. "But I've also worked with middle- or upper-class families who thought that I was supposed to provide the therapy that would make the difference for their child rather than realizing they were the ones who would make the difference."

Tanya thought a minute before responding. “You’re right. Some of the issues are related to poverty but some of the issues are shared across SES, you know, socio-economic status. There are often families who are hard to engage and we need to have some strategies for figuring out how to do that. There are a number of reasons that might be true."

Maria interrupted. “For me it seems like I come in knowing what needs to be done, but sometimes that isn’t what the family thinks needs to be done. I’m not quite sure what to do when that happens.”

"I guess," said Miko, "that since we're supposed to focus on the family's priorities and concerns, that's where we have to start, right?"

Everyone looked at Tanya. "Right," she said. "That's true for all families, but especially when we have families who have not had positive relationships with professionals. We need to show them that their concerns matter. It may be hard at first and they may not open up to us for a while, but it is important to be aware of this when you begin working with families. We build outcomes based on their concerns and priorities, but we also need to address their concerns throughout our time with the family."

Tanya continued. “If families need things that are outside of First Steps that we can’t provide, we can still provide information about who in the community can help them. In those situations, we don’t want to take over, but we do want to make sure that families have the information for them to do what they need to do. We’ll talk about boundaries later, but it can be really hard to figure out how to do this. I know from experience, when I used to just ignore their concerns and focus on my own priorities or what the team thought the child needed, the family never really became engaged and I know they saw me as just one more person telling them what to do.”

Beth nodded. “That’s happened to me and because I don’t know what to do, I ended up focusing on the child or going ahead with my own agenda, just like you said. Part of it is that I don’t know what resources are available in every community where I work, so sometimes I don’t have much to offer.”

“It takes time to figure out the resources in any community, but it’s worth the investment,” said Miko. “A couple of times I have been able to tell families where to go for help or who to call and it made a difference in our relationship. The same thing has been true when I’ve worked with families whose biggest concerns weren’t the same as mine. When we focused on the family’s priorities, you could see the family really feeling like they were part of the team.”

Tanya nodded in agreement. "Another thing to think about, especially for families with a lot of risks, is to build on their strengths," said Tanya. "What do they feel good about? What are they doing well? Sometimes it initially might be hard to find strengths but we have to start there because every family has strengths."

First Steps Belief #2:
Effective Services are Designed Around and Promote Family Strengths

All families have strengths. Families must be involved in the identification of supports and services that are meaningful to them. Promoting family strengths builds confidence and competence that will further enhance the child’s development. Each family’s strengths must be valued, accepted, and incorporated into the IFSP process.

"This is kind of a silly analogy," said Maria. "But I recently tried to take an exercise class that was really hard for me. One of the instructors gave me lots of feedback for what to do differently, but she also told me everything that I was doing well. Somehow she was able to link

my strengths to what I still needed to learn and it made me feel confident even though I knew I was struggling. I think about that with families sometimes. Parenting a young child always brings challenges and parenting a child with a disability is even harder. If it just feels as if we're telling them they're doing it wrong, rather than acknowledging all of their strengths, it's easy to see how they might feel hopeless. Even though I know this, I still don't always know how to do it."

“Good analogy,” said Tanya. “Building on strengths is something we should do with every family. With some families it’s easier than with others but it’s really important for all families.”

Parent Perspective on Family Capacity

This video depicts a parent describing the importance of connecting intervention to the family’s concerns and priorities.

REFLECTIVE QUESTIONS

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

1. How might the different risk factors affect a family’s participation in First Steps?

2. Think about the families you work with in early intervention. Name three risk factors you frequently find in families you serve.

3. Part C of IDEA provides guidance about the types of services and delivery of services to children and families, but what aspect about providing services is missing in these requirements?

Module 5 Tab 2: Families with Risks

Landy & Menna (2006) include a chapter in their book entitled "Reaching and Engaging Hard-to-Reach Families." The content of the chapter addresses questions about how to engage families. One part of this chapter talks about "readiness for change." The model for change addresses how to meet the family where they are and how to identify the stage they are in. Although it is a more general model, it can be applied to early intervention and home visits.

Developmental Model of Change (adapted for early intervention)

- **Stage 1: Pre-contemplation.** Families may not know the child has a disability or don't know what that will mean.
- **Stage 2: Contemplation.** Families may be willing to go through the assessment process but are still not sure what it means.
- **Stage 3: Preparation.** Families start to try things the providers have shown them.
- **Stage 4: Action.** Families begin embedding intervention into targeted daily routines.
- **Stage 5: Maintenance.** Families are embedding intervention into targeted and new routines.
- **Stage 6: Termination.** Families transition out of the system feeling competent and capable to support their child's development.

Source: Prochaska, J. O. (1999). How do people change, and how can we change to help many more people? In B. L. Duncan, M. A. Hubble, & S. D. Miller (Eds.), The Heart and Soul of Change: What Works in Therapy? (pp. 227-255). Washington, D.C.: American Psychological Association Press. As cited in Landy & Menna (2006) (pp. 179-180).

In the first stage, families may not know that there is anything wrong or may not understand that they might need to do something differently.

In the next stage, families begin to recognize that there might be a problem and start thinking about the idea to make changes.

The third stage is when families begin to actively engage in the process and start to think about what those changes might be. In this stage families might try a few of the activities the providers have suggested or shown.

In the fourth stage families are completely on board with making a change and embedding intervention (as identified in the IFSP process) into their families' daily routines and activities.

The fifth stage is when families can expand what they've learned with the providers and then families are not only embedding strategies into the targeted activities and routines; they can see opportunities to use those strategies in other times of the day.

The last stage, which hopefully coincides with transition out of First Steps, is when the family is able to continue what they are doing with the child and can benefit from the next program or

system of supports that comes after First Steps. The family will probably need some input from experts and a strong support system, but at this point, they know how to get the information they need and have a strong support system in place that will change as the child continues to grow and change.

FAMILIES EXPOSED TO TRAUMA

Another important consideration for professionals working with young children and families is exposure to trauma.

Trauma refers to experiences that cause intense physical and psychological reactions to stress. It can refer to a single event, multiple events, or a set of circumstances that are physically and/or emotionally harmful or potentially harmful and result in lasting adverse effects on an individual's physical, social, emotional, or spiritual well-being.

A traumatic event can be a scary or dangerous event. An event can be traumatic when we face or witness an immediate threat to ourselves or another, and it is often followed by serious injury or harm. When this happens it can cause emotions such as fear, loss, or distress. Sometimes people experience these types of strong negative emotions in reaction to the experience or because the person may not have the ability to protect or stop the event from happening.

The **Adverse Childhood Experiences (ACEs) Study** is a research study conducted by the American health maintenance organization Kaiser Permanente and the Centers for Disease Control and Prevention, initially published in the American Journal of Preventative Medicine. The study has demonstrated an association of adverse childhood experiences (aka childhood trauma) with health and social problems across the lifespan, including:

- *Adverse childhood experiences are common. For example, 28% of study participants reported physical abuse and 21% reported sexual abuse. Many also reported experiencing a divorce or parental separation, or having a parent with a mental and/or substance abuse disorder.*
- *Adverse childhood experiences often occur together. Almost 40% of the original sample reported two or more ACEs and 12.5% experienced four or more.*
- *Compared to an ACE score of zero, having four adverse childhood experiences was associated with a seven-fold (700%) increase in alcoholism.*
- *About two-thirds of individuals reported at least one adverse childhood experience; 87% of individuals who reported one ACE reported at least one additional ACE.*

Source: Centers for Disease Control and Prevention – Kaiser ACE Study

Reactions to a traumatic event can have lasting effects on the individual's daily functioning including possible changes in a person's mental, physical, social, emotional, and/or spiritual health. It is important to keep in mind, not all overwhelming or life threatening experiences are considered traumatic. Each person may interpret their unique experiences differently. A life experience that is traumatic for one person might not be traumatic for another.

Natural disaster, exposure to drug and alcohol abuse, exposure to physical, verbal or sexual abuse, community or home violence, homelessness, serious illness, death of a loved one, economic stress and poverty are just a few examples of potentially traumatic events for children and families.

While many of the examples listed above may be more easily thought of or identified as traumatic, other events might be less obvious when thinking about the potential of traumatic impact. For example, many families might need to relocate due to job changes, financial hardship, or military involvement. While these are fairly common occurrences for some families, they could have a lasting traumatic impact. It is also important to remember that all children in foster care, independent of why they might have entered foster care, have experienced changes in caregivers and living situations, and it is important to consider how these events may have made an impact.

Another way to understand and define trauma may be by remembering the "Three E's of Trauma," developed by the Substance Abuse and Mental Health Administration (SAMHSA). The "Three E's of Trauma" are: Event, Experience, and Effect.

THE THREE E'S OF TRAUMA

Event
The "Event" refers to the threat or actual experience of harm which may occur once or multiple times to the individual. Some events may include abuse, neglect, death of a loved one, or natural disaster.

Experience
The "Experience" refers to the individual's unique perception of the event described above – remember, an event that is scary or overwhelming to one individual might not be for another. In this domain, you are looking to understand the individual's potential experience or perception of the event. Some feelings the individual might experience include shame, isolation, betrayal, fear, etc.

Effect
The "Effect" refers to the impact the event and experience has upon the individual. The impact can be short-term or long-term and it may come on immediately or show up later. The effect and experience of the event might result in new or increased problems in social or family relationships, changes in sleep, eating, or mood, and difficulties thinking, concentrating, and/or expressing emotions.

“Child trauma” refers to a scary, dangerous, violent, or life threatening event that happens to a child (0-18 years of age). This type of event may also happen to someone the child knows and the child is impacted as a result of seeing or hearing about the other person being hurt or injured.

When these types of experiences happen, the child may become very overwhelmed, upset, and/or feel helpless. These types of experiences can happen to anyone at any time and at any age; however, not all events have a traumatic impact. When these stress symptoms develop, they happen automatically (i.e., are not in the child’s conscious control) as the child attempts to manage negative emotions (like fear) that emerges in response to memories of the event. The difficulties or stress symptoms can present immediately or show up later. They may also continue for days, weeks, or months after the traumatic experience and/or may resurface at different periods throughout a young person’s life. Some children may be more susceptible to developing traumatic stress reactions than others.

Trauma signs and symptoms in young children can take many forms. Understanding these signs and symptoms as trauma related depends upon sensitive information gathered from the child, family, and anyone else involved with care of the child. That said, the signs and symptoms listed below must always be considered in the context of a young child's history, caregiving system, supports, etc. and with recognition that these symptoms could also be symptoms unrelated to trauma.

Trauma Signs and Symptoms for Children Birth-Age 3

- Eating disturbance
- Sleep disturbances
- Somatic complaints
- Clingy/separation anxiety
- Feeling helpless/passive
- Irritable/difficult to soothe
- Constricted play, exploration, mood
- Repetitive/post-traumatic play
- Developmental regression
- General fearfulness/new fears
- Easily startled
- Language delay
- Aggressive behavior
- Sexualized behavior
- Talking about the traumatic event and reacting to reminders/trauma triggers

Source: *The Center for Early Childhood Mental Health Consultation (CECMHC) and partner, The Georgetown University Center for Child and Human Development (GUCCHD), Washington D.C. Module 3: Trauma Signs and Symptoms in Infants, Toddlers, and Young Children.*

Extensive research on the biology of stress now shows that healthy development can be derailed by excessive or prolonged activation of stress response systems in the body and brain. Such toxic stress can have damaging effects on a child's learning, behavior, and health across the lifespan.

Toxic Stress Derails Healthy Development

This video illustrates the long term effects of toxic stress for children exposed to trauma.

Providers aware of the impact of trauma on family relationships and functioning can help members access supports and treatments that focus on all family members and work to stabilize the whole "family unit". Look for family-informed trauma treatments that:

- Promote safety for all family members and prevent exposure to further traumas
- Optimize the strengths of the family's cultural or ethnic background, religious or spiritual affiliation, and beliefs to support recovery
- Link families to essential community resources
- Educate families on the signs of posttraumatic stress and how it can affect the family
- Help family members talk together about their traumatic experiences and how they were impacted

The National Child Stress Network has more information on trauma informed care to assist families and children.

THE FIVE PROTECTIVE FACTORS

Children are at greater risk of maltreatment when families are under a lot of stress. Every family experiences challenges and stress, but some cope better than others. There are many reasons why families handle stress differently, but one has to do with protective factors. Numerous studies have shown that the presence of these protective factors can reduce the likelihood of abuse and neglect.

Protective factors are attributes that serve as buffers, helping parents who might otherwise be at risk of abusing their children to find resources, supports, or coping strategies that allow them to parent effectively, even under stress. Families thrive when protective factors are robust in their lives and communities. By providing parents, child care professionals and others who work with children more information about these protective factors, we can help build protective factors in families with young children, building on family strengths and promoting optimal child and youth development.

The Center for the Study of Social Policy (CSSP) identified five Protective Factors that, when present, increase the overall well-being of children and families. Extensive evidence supports the common sense notion that when these Protective Factors are present and robust in a family, the likelihood of abuse and neglect diminish. Research also shows that these are the factors that create healthy environments for the optimal development of all children.

As a professional working with families every day, it is important to have a basic understanding of the Five Protective Factors and be able to recognize when a family is in need of support and resources to care for their child.

Protective Factor 1- Concrete Support in Times of Need

Families need support and services that address their needs and help minimize stress caused by challenges. Parents need access to the types of concrete supports and services that can minimize the stress of difficult situations, such as a family crisis, substance abuse, or stress associated with lack of resources. Building this Protective Factor is about helping to ensure the basic needs of a family, such as food, clothing, and shelter, are met. It can also include connecting parents and children to services, like domestic violence shelter or substance abuse counseling, in times of crisis

Protective Factor 2- Parental Resilience

The way parents respond to stress is often more important than the stressor itself. No one can eliminate stress from parenting, but building parental resilience can affect how a parent deals with stress. Parental resilience is the ability to constructively cope with and bounce back from all types of challenges. It is about creatively solving problems, building trusting relationships, maintaining a positive attitude, and seeking help when it is needed.

Protective Factor 3- Knowledge of Parenting and Child Development

Parents need information and strategies to support physical, cognitive, language, social, and emotional development. Having accurate information about raising young children and appropriate expectations for their behavior helps parents better understand and care for children. It is important that information is available when parents need it, that is, when it is relevant to their life and their child. Parents whose own families used harsh discipline techniques or parents of children with special needs may require extra support in building this Protective Factor.

Protective Factor 4- Children's Social and Emotional Competence

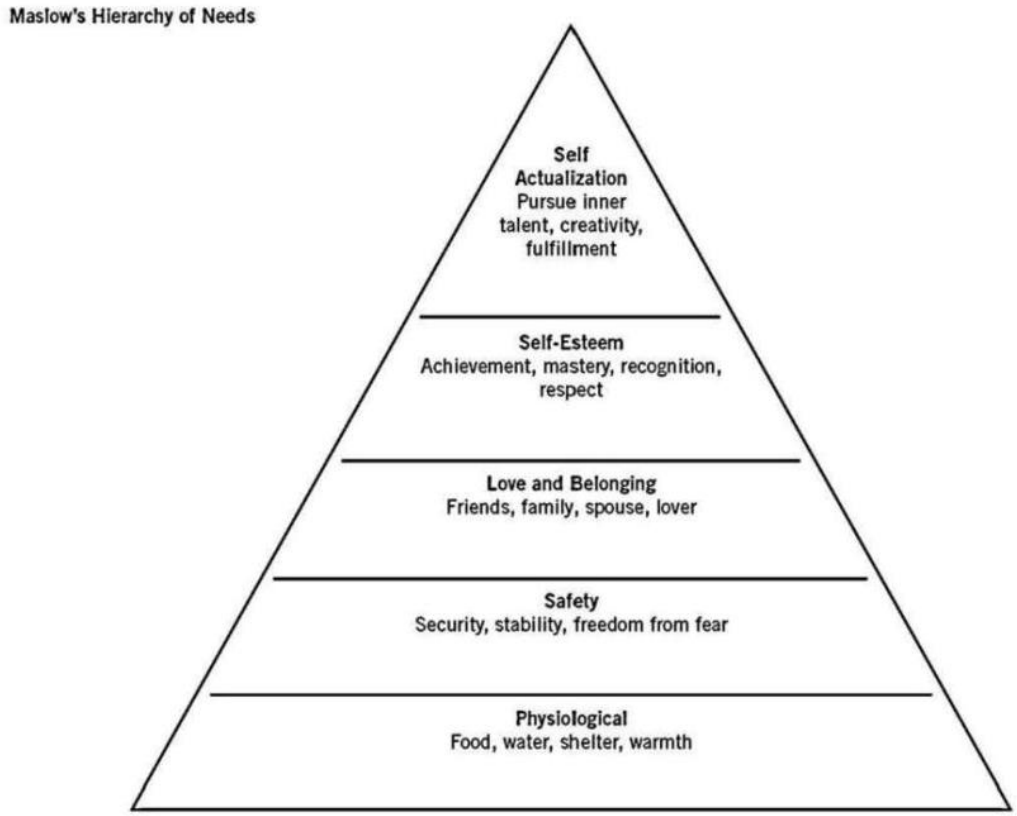
Children need help expressing their feelings and emotions. Parents can help children learn to communicate clearly, recognize and regulate emotions, and build and maintain relationships. A child's ability to interact positively with others, to self-regulate, and to effectively communicate his or her emotions has a great impact on the parent-child relationship. Children with challenging behaviors are at a greater risk of abuse; therefore, early identification is important to keeping their development on track and keeping them safe. Also, children who have experienced or witnessed violence need a safe environment that offers opportunities to develop normally. Through appropriate interventions, children can learn positive social and emotional skills and have improved outcomes.

Protective Factor 5- Social Connections

Families need to build and maintain positive relationships that can provide emotional, instrumental, informational, spiritual, and other helpful support. Friends, family members, neighbors, and other members of a community can provide emotional support and concrete assistance to parents. Because isolation is a common risk factor for abuse and neglect, parents who are isolated need support in building positive friendships. Social connections help parents build networks of support that serve multiple purposes: they can assist parents in developing community norms around childrearing, provide assistance in times of need, and serve as a resource for parenting information or help solving problems.

BETH'S STORY

"I think I said this before, but the Landy book talks more about the psychological kind of intervention but I think it's a really nice way to think of the process for families coming to First Steps," said Tanya. "As service coordinators and providers, we get early intervention and what it is supposed to 'look like' because we do it every day. We come in ready for the IFSP meeting or ready for a home visit, yet sometimes we forget that this is a whole new and often scary world for families. Something else that has helped me a lot is to visualize *Maslow's Hierarchy of Needs* when I'm thinking about where the family is. Sometimes, as professionals, we are not in the same place as the parents, and we need to step back. If we want our visits with families to be meaningful, we need to think about what the family needs right now and build on that."



Source: National Institutes of Health

Tanya continued, “I know we all want to be empathetic and supportive but we really do expect that the family will be able and ready to jump on board with our home visits. We always think about meeting the *child* ‘where he or she is’ developmentally, but we don’t think about where the *family* is at and whether or not they are ready for what we want to do to support them.”

“I need to read Landy’s book again and think about this some more but it makes sense to me,” said Maria. “I never thought about it that way but when you talked about those first stages, a number of families came to mind.”

Beth jumped in. “Me, too. As a provider I came in and expected the family to be ready to implement intervention in their daily routines and activities. But sometimes they weren’t ready and they were in those first stages where they really didn’t understand what we wanted them to do or maybe even why we wanted them to do it. I hate to confess, but then I felt frustrated with them and annoyed and even though I tried to hide that, I’m sure they felt it.”

“I think that’s true for me too,” said Maria. “I didn’t want to feel frustrated with them but I didn’t really know how to respond or what to do. Sometimes that affected the entire relationship and I never felt like we really connected or we were really on the same team. I didn’t understand what was going on.”

Maria continued. “I thought that since we did the Routines-Based Interview™ and the goals were functional for the child, then the family would be on board immediately. Since I thought I’d done it ‘right’ it had to be the family that was wrong, but I was the one that was wrong! I sometimes thought to myself they just don’t care or something kind of judgmental like that, even though I knew I was really frustrated that I wasn’t really connecting,” said Maria.

“I guess it makes me feel better to know that I’m not the only one who has had those feelings,” said Miko. “It does help to have another way of thinking about it but I still don’t know what I should do when that happens.”

“This is exactly the kind of conversation I had hoped that we’d have,” said Tanya. “Thanks for being so honest about how you feel. It’s hard to acknowledge those feelings, but it does make it easier to address them. Really, we have to meet families ‘where they are’ and not expect them to change what they are doing or try something new when they are not ready. The question then becomes what do *we* do in our time with the parent and child that supports both of them and helps the parent move through those stages?”

“Exactly!” said Beth. “If I knew what to do and it felt productive, I wouldn’t feel so frustrated, which would make it much easier to really form a positive, collaborative partnership. So, what do we do?”

“Well the Landy book also talked about some variables - like the fact that a family has a positive parent-child relationship or the parent’s ability to read cues from their child to respond to the child - that are better predictors of positive outcomes than other variables - like poverty,” said Tanya.

Miko jumped in. “So, what you are saying is we need to ask about the goals and the routines and see what’s going well and what’s not going well for the family. At the same time we focus on the parent’s interactions with the child and comment on all of the positive things we see happening and relate those to the IFSP outcomes if we can.”

Tanya smiled and nodded. "Exactly," she said. "You can focus a lot on the strengths of the parent in the interactions with the child because that will affect the child's development. The family's interactions provide a positive context for whatever strategies that parent uses and that sets the stage for the child's development. If we are focusing on their interactions, we're also making it easier to form a relationship with the parent and this will help the parent be willing to form a relationship with us, since what they are getting from us is positive. It may take a while. None of us can change overnight and it's a good use of our time and our skills. I think it also helps us to not be so judgmental."

The Power of Positive Parenting

In the National Longitudinal Survey of Children and Youth, Landy and Tam (1997) found that for children living in poverty and even those with multiple risks, positive parenting was a protective factor. Those children scored higher on developmental measures than the children who had few risk factors but negative parenting.

Source: Landy, S., & Tam, K. K. (1997). Yes, parenting can make a difference in the development of Canadian children. In Statistics Canada, Growing up in Canada: National Longitudinal Study of Children and Youth (pp. 103-118). Ottawa: Human Resource Development Canter, Statistics Canada. As cited in Landy & Menna (2006) (p. 7)

"That feels right to me," said Beth. "Focusing on the strengths of the parent and the strengths of the child—not the deficits. When we focus on the strengths, we are really implementing a family strengths-based model. We're meeting families ‘where they are' and supporting them. We don't expect the children to learn new things without having time and practice. I know I don't learn new things without time and practice but I think I was expecting families to change immediately. I think this will help me be more empathetic to what the family is experiencing rather than coming in with a long ‘to-do list.'" Beth sighed. “Of course, it will take time and practice to really get comfortable with this and to break some of my old ways of thinking about things."

“Right,” said Tanya. “Just like it will take the families some time and practice to begin thinking about what it means to have a child with a disability, what a family-centered model is, and what it means for their daily lives. That’s a lot to deal with. It’s no wonder why it may take some families some time.”

Tanya continued. “Another thing to think about is instead of talking about the home visits being difficult, think about what makes the services difficult to deliver to the families. It will be different for different families but in general the issues fall into two categories – practical issues or issues related to beliefs or values. The practical issues are things like not having a phone, not being able to read, or having an irregular work schedule. Although these can present challenges,

you know they exist and they can usually be addressed by being flexible or finding resources. Issues related to values and beliefs can be harder to address because you can't see them. These are things like believing that professionals aren't to be trusted, or that it's not OK to need help, or even that no one else should know 'our business'.

It is important to acknowledge the family's values and beliefs but we are not asking the family to change them in order to have early intervention services. If we focus on providing a family-centered model that addresses the family's concerns and priorities, which is what we're supposed to do, then we can focus on the family's strengths and what is going well. This is how we form partnerships with all families."

"One more thing," said Tanya. "We only know what we know and we do the best we can. Sometimes we don't get to see the results of our work because it happens later but investing in families is always important and we never know what we might do or say that will have a lasting impact—either positively or negatively. So we should do our best to make it positive." Tanya stopped and smiled. "Can you tell that this is really important to me? I feel very passionate about our work and think that we can and do make a difference."

Miko smiled. "I can tell and it's one of the reasons I love working in First Steps. Almost everyone I've come in contact with feels passionate about what we do."

Tanya continued. "Hey," she said, "this reminds me of a statement from the Landy book that said: 'Intervention is with, not to.' "(As cited in Landy & Menna (2006), p. 430).

"I like that," said Maria. "What a great way to remind myself that I need to join the family and together we make this journey. It's not something that I can or should impose on them."

"I agree," said Miko. "When I find myself thinking negative thoughts, I'm going to try to remind myself that I need to try to find a way to connect with families. I think that will help change my perspective," said Miko.

REFLECTIVE QUESTIONS

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

1. This section talked about "meeting the family where they are" and discusses the six stages of change for families. What are some strategies you can use to help support a family in stage one and guide them to stage two?

2. Supporting positive parent-child interactions is an important outcome in early intervention. Name three positive interactions you might look for when working with a family.

3. Think about two children both dealing with a serious illness and receiving early intervention services. How could the Three E's look different for each of them?

4. Why is it important for early interventionist to be aware of signs of trauma and how might this skillset assist you as you engage families in services?

Module 5 Tab 3: Cultural Sensitivity

Quote

"The old proverb notwithstanding, we cannot put ourselves in someone else's shoes; or, rather, we can, but it's *still* our own feet we will feel."

Source: Storti, C. (1989). The Art of Crossing Cultures (p. 51). Yarmouth, ME: Intercultural Press. As cited in Lynch, E. W., & Hanson, M. J. (2004). Developing Cross-Cultural Competence: A Guide for Working With Children and Their Families (3rd ed.) (p. 42). Baltimore: Paul H. Brookes Publishing Co.

Cultural sensitivity is a set of skills that enables us to learn about and understand people who are different from ourselves, thereby becoming better able to serve them within their own communities. Cultural sensitivity is important because it allows us to effectively function in other cultures, allows us to respect and value other cultures, and can reduce cultural barriers.

RESPECTING CULTURE

Early intervention professionals work with families from a myriad of backgrounds, cultures, religions and family compositions. Each family has their own unique values and beliefs. Cultural Competency is the ability to honor and respect the beliefs, languages, interpersonal styles and traditions of each family we work with.

It is important to recognize our own values and beliefs BUT it's also important to set these aside as we work with families. One place where culture difference may appear is around child rearing, including feeding, discipline, and sleeping practices. Another cultural difference may be the early intervention emphasis on family involvement. This may be strange to families of different cultures. Some families may simply agree to recommendations made by professionals, as they are not comfortable with their right to question or to contribute their own ideas.

While being aware of and honoring cultural differences, it is important not to let generalizations take the place of truly getting to know the family, exploring with them their family life and the priorities they want to address with early intervention.

Early intervention should be family-centered. Being family-centered means acknowledging there are as many differences within cultures and ethnicities as there are among people. While you don't want to impose your beliefs onto the family, you also do not want to assume that the behaviors you see are a result of race, ethnicity, or culture.

Before becoming culturally aware and competent, it is also necessary to discuss diversity and to recognize that it is all around us and comes in many forms. When we think about diversity we normally just think about race and gender but let's expand your definition.

Diversity is accepting that each individual is unique, and recognizing individual differences. Diversity is also understanding each other and moving beyond simple tolerance to embracing and celebrating the rich dimensions of diversity contained within each individual. The concept of diversity encompasses acceptance, understanding and respect.

Dimensions of Diversity. Diversity is not just tied to race, culture, or ethnicity – it is multidimensional. Early intervention professionals who work with families of children with disabilities will encounter families who differ on every dimension. Sometimes differences in socio-cultural factors such as socioeconomic status (SES) or education level might be challenging for early intervention professionals and families. Family values, communication abilities and styles, and belief systems, among other variables, may impact the professional/family working relationship.

Robin McWilliam provides ways professionals can recognize and respect diversity, including differences in a family's:

- Style of communication
- Belief about family roles and routines
- View about children and child rearing
- Belief about disability or risk conditions
- View about strategies and change

Defining Cultural Competence. Cultural competence begins with an understanding of one's own values and beliefs. The next step is to begin to learn about the values and beliefs of others. Cross-cultural competence is having the knowledge and skills to maintain a process that will increase your own understanding of the similarities and differences between yourself and others in areas such as values and beliefs or abilities and lifestyle. Lynch and Hanson refer to the range of beliefs as a cultural continuum.

Cultural Continuum

Small family units ……..Extended family and kinship networks
Individuality ……...Interdependence
Focus on early independence ……Nurturance of young children
Time is measured ……...Time is given
Emphasis on youth and new ……..Respect for age and tradition
Ownership by individual ……...Ownership by a community
Equality ……Clear gender and generational roles and responsibilities
Focus on control ……Harmony and respect for nature

Source: Lynch, E. W., & Hanson, M. J. (2004). Developing Cross-Cultural Competence: A Guide for Working with Children and Their Families (3rd ed.) (p. 50). Baltimore: Paul H. Brookes Publishing Co.

Cross-cultural competence is a process, not an endpoint. It is not a set of skills that can be checked off a list and considered mastered. Rather, it requires lifelong attention.

There are a number of steps that individuals can take to increase and enhance their skills in cross-cultural competence (McWilliam, 2010, pp. 154-155):

1. **Self-awareness.** Consider one's own values, biases and behaviors.
2. **Education.** Learn more about others' cultural and socio-cultural perspectives through reading books, the arts and using technology; through talking, socializing and working with individuals from another culture; by participating in the daily life of another culture; by learning the language of another culture.
3. **Practice.** Apply one's self-awareness and the information learned about other cultures in practice.

One's race, language, beliefs, traditions, life practices and other attributes might be material or immaterial to each individual and family.

What is important for an early intervention professional is determining which of these components are significant to each family, learning how they are expressed and finding ways of interacting and intervening that fit within the family's cultural framework (McWilliam, 2010, pp. 151-153).

BETH'S STORY

Maria, Beth and Miko arrived for their next get-together at the same time. Tanya arrived a few minutes later.

Maria said hello to everyone, then commented, "I've thought a lot about our conversation last week. Thanks for bringing us together again."

"It has really been nice to talk to each other and learn more about how to set up a meaningful home visit with families," commented Tanya. "Today, I wanted to share some things that I read

in another book by Lynch and Hanson. It is a good book to read, if you have time and are looking for something to read about cultural differences and working with families. They talk about what it means to be culturally competent. They also have a lot of information about different cultures that would be helpful for us, like attitudes about disability and education. Did you have any specific questions?"

"Not really," said Beth. "I've heard the term 'cultural competence' a lot but I don't really know what it means."

"Can I answer that?" asked Maria.

Tanya nodded.

"It means first knowing what your own values and beliefs are and understanding that your beliefs aren't the one right set of beliefs. That doesn't make them any less important to you. But every person has a set of values and beliefs and those are as important to that person as yours are to you. If you can really understand that, becoming culturally competent isn't really difficult."

Maria continued. "It does take some time and effort but it's interesting to learn about what others think and feel. If you don't really understand that and you can't get past the idea that you are right and others are wrong, becoming culturally competent is virtually impossible. So the first step is to really think about what you believe and what are your values," said Maria.

First Steps Belief Statement #3
Effective Services are Culturally Competent

Diversity is valued and providers of early intervention services must be responsive to and respectful of the cultural diversity of each family served in the system. Customs and traditions are an important part of family life.

Beth nodded in agreement before speaking. "I know that one of the First Steps Belief Statements is about cultural diversity, but sometimes it feels like even though I know that people from different cultures or backgrounds may have different beliefs, I'm not sure how to address the differences."

Miko nodded. "I know that my parents really struggled with that when they first got here and often were made to feel as if being different meant being wrong. When I disagree with some of the things parents are doing I try to remind myself of my parents' experiences and to distinguish between what might be bad for the child versus what might just be different. I think it's easier for me since I grew up with Japanese values and beliefs but also the broad American beliefs. I've had a lot of practice thinking about the differences and similarities."

"That's true for me too," said Maria. "For my work with First Steps I try to figure out what are the beliefs or values that affect parenting. They affect pretty much everything – what foods the

child eats, how the child is dressed, and who is the primary decision-maker for the child. It also affects what kinds of goals are considered functional. In the broader American culture, independence is valued. In general, babies and young kids are expected to feed themselves as soon as they physically can and to sleep in a room away from their parents. For cultures where value is placed on interdependence, parents may want the child to sleep in their room or even in their bed. They may also continue to feed the child long after the child is physically able.”

"That's exactly what I mean!" exclaimed Beth. "I've been in meetings where the providers were really pushing independent feeding and the parents just weren't interested. Or they nodded yes, but continued to feed the child. I never quite understood that but I have a better idea of it now."

Tanya added, "You're bringing up a couple of issues. One is related to developing functional outcomes but the other is related to cultural differences in parent-professional roles and communication. In some cultures it would be considered rude to disagree with the professional so parents don't voice their disagreements."

Tanya continued. "Body language is also different. When I nod my head I mean ‘I agree with what you've said.' In some cultures when someone nods a head it means, ‘I heard what you said' but it doesn't mean agreement."

"I didn't know that," commented Beth. "It seemed really confusing to have parents nod yes and then week after week not do anything different in some areas, even though in other areas they were embedding strategies into their routines and activities," said Beth. "Now I'm starting to understand. And when I have to use a translator it makes communication even harder."
Maria nodded. "When I was young I used to translate for my grandparents sometimes," she said.

"Not for anything as important as this, but in restaurants and stores. It was often uncomfortable. The people would look at me rather than my grandparents and it just felt awkward. They didn't like it either and sometimes chose to stay home instead of eating out or going shopping with me."

Beth spoke next. "Since I have been working in First Steps, I have had a translator just a couple of times but it seemed really cumbersome and confusing. I don't remember now if I looked at the parents or the interpreter but I'll remember to look at the parents next time," said Beth.

"We've had a hard time finding translators for some of the foreign languages," said Miko. "I've had colleagues who wanted an older sibling or other relative to interpret but I wasn't sure if that was a good idea or not."

Tanya replied, “The First Steps program requires translators for all activities involving parental rights. Some activities that require a translator are evaluations of the child, assessments of child and family, and IFSP meetings. A good translator is someone who is fluent in both languages and knows a lot about the First Steps program.”

“How do I find out more about cultural differences and how to effectively work with translators?” asked Beth.

Tanya thought a moment, then spoke. "Books designed for early intervention or special education are a good place to start. You can also read fiction and nonfiction stories written by members of a particular culture that you are interested in. You can find out a lot that way about how others think and feel. It's important not to form stereotypes since each person is different and no two people have exactly the same set of values and beliefs. That's even true for people in the same family. But it's a good way to explore some of those differences. You can also talk to people who are from other cultures. Usually people like to talk about their beliefs, especially if they know you're trying to become more culturally competent," responded Tanya.

“I agree,” said Miko. “One of the things that I run up against in my work is that it seems like there are groups of people who share a set of beliefs and if you aren’t part of that tight-knit community then you are an outsider and not to be trusted. I know there are children and families that we could be helping but we haven’t made a connection with them yet.”

Beth nodded, then spoke. "When I was working in a small, rural community this would happen sometimes. But it also happened when I worked in the city, too. I guess no matter where you live, there are tight-knit groups. Do you have any strategies for addressing that?"

"Yes," Tanya replied. "I do have some strategies. You bring up the idea that cultures can be as large as a county or as small as one's own religion or political view. We share a culture of being early interventionists and we have a set of beliefs related to that. We probably have lots of differences because we aren't the same gender, we have different professions and we have differences related to our ethnicity, just to mention a few."

"One of the ways to build trust as an early interventionist is to build relationships in the community," said Tanya. "We might get involved in some community activities and get to know more about the different cultures in the community where we live. There are often lots of supports in the communities and we might think about how our services can complement those supports rather than compete with what's already there."

Tanya looked at the clock. "Oh, I hate to leave now but I have another meeting in 15 minutes. I hope this was helpful."

Miko, Beth and Maria all answered at once with a resounding, "yes."

"I still have more questions, though," said Beth. "Can we meet again?"

"That's fine with me," said Tanya. "We didn't get to any of the topics under ethics so we can start there. Why don't you each go to your professional organization's website and read the code of ethics. How about next week at the same time?" asked Tanya.

“Works for me,” said Maria.

“Me, too”, said Miko.

“Ok, we’ll all meet here next week. Thanks a lot, Tanya” said Beth as they walked out the door.

Aracelly and Elizabeth

In this video, Aracelly shares her family's journey from the time her daughter, Elizabeth, was born to adulthood.

REFLECTIVE QUESTIONS

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

1. Your own beliefs and values are as important to you as the beliefs and values of the families you work with. Identify at least four beliefs and values that you have. How would you approach families whose beliefs and values are different from yours?

2. Explain the statement, "You must distinguish between what might be bad for a child versus what might just be different."

3. Explain how diversity can be multidimensional and how having an understanding of this impacts the work you do with children and families?

Module 5 Tab 4: Ethics

Quote

"Services for infants and toddlers are often provided in families' homes. . .
The level of trust that families place in early interventionists is extraordinary. Professionals, therefore, must adopt the strictest codes of both ethical and respectful behavior. Ethics are principles of appropriate conduct that are part of every profession."

Source: Hanson, M. J., & Lynch, E. W. (2010). Working with Families from Diverse Backgrounds. In R. A. McWilliam (Ed.), Working with Families of Young Children with Special Needs (p. 167). New York: Guilford Press.

When families are referred to First Steps, they are often at different stages in their lives. Some families will be dealing with the news of their child's disability through denial or disbelief; other families are dealing with the news of their child's diagnosis with relief to finally have information about their child; and still other families may be unsure about what they are feeling and what will happen next.

As First Steps professionals, it is important to meet the family where it is and begin to build a supportive relationship with all families regardless of race, color, national origin, disability, age, gender, marital status, veteran status, or religion.

Service coordinators and providers play an important role in early intervention services and their work with families. Because of this, the highest standard of professional behavior should be maintained at all times. When providing early intervention services, it could be easy to cross over these boundaries and experience problems communicating with families.

Families can also experience significant problems when relationships are not monitored carefully. Families may become overly dependent on a service coordinator or provider and fail to understand their own responsibilities, or understand the appropriate responsibilities of other professionals.

First Steps professionals must refrain at all times from divulging any information concerning the child and/or family to an unauthorized person(s) without the informed, written consent of the responsible parent/legal guardian.

It is critical that First Steps providers be knowledgeable of this requirement as well as abiding by all federal, state and local laws, rules, regulations, and policies related to this program including, but not limited, to **34 CFR Part 303** (Early Intervention Program for Infants and Toddlers with Disabilities), **34 CFR Part 99** (Family Educational Rights and Privacy Act or FERPA) and **42 U.S.C. Ch. 126, Sections 12101-12213** (the Americans with Disabilities Act or ADA).

As the First Steps program is governed by these federal regulations and other state statutes, it is also essential that First Steps professionals stay connected with the Department of Elementary and Secondary Education (DESE) as the regulations and rules may be revised or amended from time to time.

BETH'S STORY

Once again, Beth, Miko and Maria arrived at the same time for the meeting. They said their hellos, put their backpacks and purses away and pulled out their list of topics. They each took out their Code of Ethics, according to their professional organizations.

"Did you find your code of ethics helpful?" asked Beth.

Miko answered first. "For physical therapy, mine was helpful to some extent, but it wasn't specific enough for me to answer all of the questions, particularly the questions about what are appropriate boundaries and taking or giving gifts to families."

"That's pretty much what I found, too," said Maria. Just as the conversation started, Tanya arrived at the table.

Beth chimed in. "Perfect timing, we were just talking about our own professional organizations and their codes of ethics. We were just saying that they are not very specific to situations that we deal with every day."

"Yes," agreed Tanya, "the codes of ethics are much broader and can be applied to anyone who is in that profession. Since people can work in lots of different settings they can't be too detailed since what might be appropriate in one setting might not be in another—or might not even come up. So, let's get started."

Tanya continued. "You all raised some issues about ethics, which reminds me of when I worked for the early intervention program in Texas. The company I worked for gave us information on ethical practices. I remember quite a bit of it and have found it helpful over the years. I guess thinking about ethics is something that all of us in early intervention need to do."

Tanya continued, "Although we all have our own set of personal ethics that guide our behavior, working with families and children often presents ethical dilemmas. We need to have a way to think about the issues as they come up and to have a plan to address potential problems. Most of us, when confronted with an ethical issue, feel uncomfortable."

"Some things are just plain wrong and those aren't the problem because what we should do is clear," explained Tanya. "But other times, things aren't clear and we may worry about hurting someone's feelings. When I read through your topics and thought about the issues I've faced it seemed clear there are three areas we should talk about: setting boundaries, taking or giving gifts and confidentiality. I think boundaries are the hardest, so let's start there. Do any of you have any examples to start us off?"

"I do," said Beth. "Some of the families I work with don't have a lot of money and really go from paycheck to paycheck struggling to keep food on the table. There have been a couple of times when a mother confided to me that she was short that month and didn't know what she was going to do. I provided information about what was available in the community and then I felt selfish for not giving them money. But, when I thought about giving the family money, it made me feel uncomfortable. I guess that's why it's an ethical issue—neither choice felt like exactly the right one."

"Great example!" said Tanya. "From my perspective what you did was exactly what you should have done. You want to connect families with community supports that provide assistance. You don't want to set up a situation where you are the actual assistance. That's not your job and doing that might make your relationship more complex. What if other parents you work with found out that you gave money to some parents but not to them? What if you gave money, but the next time it was a different professional who was asked and he or she said no?" asked Tanya.

"I'm glad now I said 'no,' but I hadn't thought it all the way through," said Beth. "I just knew I felt uncomfortable. I didn't say anything to anyone about it, though."

"You know, that's a good point you made about feeling uncomfortable," Tanya replied. "If you feel uncomfortable that's a signal. You should pay attention to that feeling. It's best if you can wait rather than immediately answer and give yourself some time to think about the potential consequences and perhaps talk to your supervisor about what to do."

"That's good advice," said Maria. "I have had other issues related to boundaries come up. Lots of families have asked me to come to their children's birthday parties or other family events. Usually if I can I try to stop by for a little while but it never feels quite right. I also struggle with buying birthday presents. Do I get one for every child where parents invite me to the party? Do I only buy a present if I go to the party? Do I buy a present for every birthday for every child on my caseload?"

"It sounds like you've answered your own question," said Beth. "If you say yes, then you have another long string of ethical dilemmas. Going to birthday parties is not part of our professional relationship. That's crossing—or at least blurring—the line between professional and personal relationships. Once you've said yes, you've blurred the relationship, and it will be harder to say no to other invitations."

Tanya jumped in. "As a service coordinator, I can tell you our agency has its own expectations and guidelines, which include the following. I brought the list since I knew we were discussing ethics."

- No employee may accept gifts or favors of substantial value from customers. All gifts of substantial value must be declined.
- Employees shall act impartially and neither give nor accept special favors or privileges, which might be construed to improperly influence the performance of their official duties.

- No employee shall solicit or accept a gift or fee for participation in any activity or program directly or indirectly related to their work.

“It helps when there are expectations in writing,” said Maria.

"You raised the issue about presents," said Miko. "I haven't been in that situation yet but I know someone who got close to one of her families and began attending family celebrations and holidays and was buying birthday presents and wedding gifts and she became a close friend. It affected her ability to provide professional guidance and support. I went on a home visit with her once and she and the mom talked about things not related to the child for quite a while. You could tell she felt uncomfortable about it but also felt like she couldn't tell the mom that they needed to focus on what they should be doing related to First Steps. The whole situation made me uncomfortable and I decided then that I wouldn't be buying presents, or going to birthday parties, or celebrating holidays with families. I'm glad now I made that decision because it seems really hard to say no after saying yes."

"That's exactly right," said Tanya. "Although we want to be friendly with families, that doesn't mean we want to be friends. Trying to be friends jeopardizes our professional relationship. We need to maintain a professional role and be as supportive as we can possibly be, within the boundaries of that role."

"OK, I think I know the answer to this but I'm going to ask anyway," said Beth. "What about things that don't cost anything? I was given tickets to a play that I couldn't use and one of the families I work with really wanted to go but couldn't get tickets. Would it be OK to give the tickets to them? Or, what if I sold the tickets to them?" Beth paused a moment, then continued. "Oh, never mind, even just saying it out loud makes the answer clear. That's not part of a professional relationship and we shouldn't do it. That would also be true for parents giving us tickets they can't use or gifts, right?"

Tanya nodded. "Yes, taking gifts of any kind is outside the boundaries of a professional relationship. That can be particularly difficult for some holidays but if all of the providers are consistent and give parents a consistent message, families will understand and it will feel fine. It's much more of a problem if various providers behave differently. Then parents don't know what's OK and what's not. That's not fair to them and our inconsistency puts them and us in awkward positions. The rule of thumb is if you're not sure it's OK, say no or say you don't know and you'll get back to them. But, if you think it might not be appropriate and part of your professional role, it's probably not."

Miko thought a minute. “That makes sense to me. It also makes it much less confusing to families and that should be one of our goals. We certainly don’t want to make their lives any harder. Can I change topics here and ask a different question?”

"Sure," said Tanya. "I think we're done with boundaries, at least for the moment. Is that OK with everyone, to move on?"

Maria and Beth nodded.

"OK, my question is about confidentiality," said Miko. "I know that we aren't supposed to give any information to anyone outside of First Steps without written consent from the family," Miko said. "That makes sense. But I just took over another provider's caseload last month and yesterday she asked me how the children and families are doing that she used to serve. I don't know if I can talk to her about them or not?" asked Miko.

Maria spoke up. "I had a similar situation when I first started. We have to be careful sharing information about families. Is this person still in First Steps?" asked Maria.

Beth replied, "No, she isn't a provider anymore. She left First Steps to go work full-time in the clinic at ABC Hospital."

"Ok," replied Maria. "Since the provider is no longer in First Steps, you can't share information about the families. Now, if the provider was still in First Steps and on your early intervention team, you would be able to share strategies you are using with the family as part of an EIT meeting. We will talk about that in the next topic (Module 6)."

"That's right," said Tanya. "You can't share any information if the provider left First Steps. You can say 'no thank you' nicely but you just can't tell people who are not in First Steps anything about your families unless you have written consent, and we only do that if someone needs to know—like school district personnel during the transition process."

Release of Information

The Family Educational Rights and Privacy Act (FERPA), incorporated by reference in the Individuals with Disabilities Education Act (IDEA), requires that the parent's signed and dated written consent be obtained for the First Steps System to share specified information (e.g., progress notes, etc.) with individuals and agencies outside of the First Steps System.

FERPA does not require that parental consent be obtained for individuals within the system (System Point of Entry staff, the child's Service Coordinator, the child's Service Providers, the Central Finance Office and the Department of Elementary and Secondary Education) to share information with one another on a need-to-know basis.

This means the Service Coordinator completes a release for each individual/agency after the family indicates information needs to be shared. This release is ONLY for individuals and agencies OUTSIDE of the First Steps system. Providers must use their own release form to obtain consent to share information with individuals and agencies outside of the First Steps system.

"Ok, what else haven't we talked about?" asked Tanya.

"It has only happened once but I worked with a family where I was worried that they were neglecting the baby," said Beth. "I wasn't sure and she wasn't being physically abused so I wasn't quite sure how concerned I had to be before reporting the family for suspected neglect."

"I will try to answer this one," said Miko. "As First Steps providers, we are all mandated reporters," he explained. "As a mandated reporter, if you suspect that a child is being abused or neglected you have to report it. I use the website hotline; it has great tips to consider."

You don't have to conduct the investigation, but if you suspect something and don't make a report and any harm comes to the child, you may be held accountable."

Beth jumped into the conversation next. "I worry that if I report the family they would stop participating in First Steps or they'll be really angry with me, especially if nothing bad was happening."

"I know that it isn't easy," said Miko, "and it would feel bad if we accused a family that was not neglecting or abusing. But, making sure the child is safe carries more weight than the feelings about the situation. Remember, before you report, you have to ensure that what you're seeing isn't just a different way of raising a child, but is harmful."

"That's good to keep in mind," said Maria. "If the family is from a different culture, particularly if they are new to this country, we should check and make sure that we understand what is happening before we report. That's just one more reason to learn about the culture of the families we work with."

"Absolutely," responded Tanya. "Though the safety of the child is what's more important, we want to avoid misunderstandings if we can."

Tanya continued. "I have to go in a few minutes but I had a couple more things from my time working in Texas that I wanted to share with you. The Texas program had an entire training module on ethics in the early intervention field. I mentioned it before, but think it's worth mentioning again. If you have a gut feeling that something probably isn't right, or if you recognize that this is an issue that you've heard about from your supervisor or in discussions about ethics with colleagues, don't say yes to the family's request. Think about the possible consequences of your actions, check to see if the agency policies or your code of ethics has something to say on the topic, and ask your supervisor for advice."

"Texas developed an acronym for the steps in responding to ethical issues. It's RADAR," explained Tanya. "I think about it as keeping ethics on our radar. I printed it out for you. Here, take a look," said Tanya as she passed around the handout explaining RADAR. "It should help the next time you're faced with an ethical dilemma."

Five-step Process for RADAR

1. **R**ecognize a dilemma
2. **A**nalyze the options
3. **D**evelop a plan
4. **A**ct according to plan
5. **R**eflect on decision

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"Sorry to cut this short but I have to run," said Tanya after everyone had finished reading the handout.

“Thanks, Tanya, this was really helpful,” said Maria.

“Yes, it was,” agreed Beth. “I hope all new providers get to have these conversations.”

“I agree with you both and maybe we can do this again in another six months or so. It was good to see you all,” said Miko as he walked out of the room.

REFLECTIVE QUESTIONS

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

1. We want to establish partnerships with families where they trust us and we can work together. What differences do you see between a professional partnership and a personal partnership?

2. You are a provider for a family who has recently moved to Missouri. The mother has asked you to stay for lunch to “get to know each other better.” How would you respond? What are some strategies you can use to help support this mother without crossing boundaries?

3. What can you do if you are uncertain whether or not a situation constitutes a report of child abuse or neglect?

Module 5 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 5 Documents.

1. DEC Code of Ethics
2. Release of Information

Module 5 Videos.

1. Aracelly and Elizabeth
2. Parent Perspective on Family Capacity
3. Toxic Stress Derails Healthy Development

Module 5 Supplemental Resources.

1. Children's Trust Fund – Protective Factors Training
2. Engaging Culturally Diverse Families
3. Head Start: Understanding Family Engagement
4. Maslow's Hierarchy of Needs
5. Parent Participation in Early Intervention
6. Missouri Department of Mental Health: Trauma Informed Pathways to the Five Domains of Well-Being
7. Missouri Institute of Mental Health. Introduction to Trauma Webinar. Presented by Dr. Patsy Carter
8. The National Child Traumatic Stress Network: The 12 Core Concepts

Module 5 Reference/Books.

1. Landy, S. & Manna, R. (2006). Early intervention with multi-risk families. Baltimore: Brookes.
2. Lynch, E. W., & Hanson, M. J. (2004). Developing cross-cultural competence: A guide for working with children and their families, Third edition. Baltimore: Brookes.
3. McWilliam, R. A. (Ed.). (2010). Working with families of young children with special needs. New York: Guilford Press.
4. The Center for Child Trauma Assessment, Services and Interventions (formerly the Center for Child Trauma Assessment and Service Planning) at Northwestern University Feinberg School of Medicine, a Treatment and Services Adaptation Center of the National Child Traumatic Stress Network (NCTSN). Retrieved 1/24/19. *What is Child Trauma?* Chicago, IL.
5. The Center for Parent Information and Resources (retrieved 1/24/19). *Basic Information about Trauma*. Newark, NJ.