

## Session 3

# Support-Based Early Intervention and Developing Ecomaps

## Introduction

In Session 3, "Support-Based Early Intervention and Developing Ecomaps," of the *Family-Centered Practices* module, participants will acquire the knowledge, skills, and expertise needed to demonstrate competence in planning and implementing support-based early intervention. Because exemplary early intervention is family centered and based on family ecology, practitioners will learn how to develop an ecomap—a graphic portrayal of a family's informal, formal, and intermediate supports. Developing the ecomap helps determine the supports, rather than the services, that will be important in developing and implementing the intervention plan for the family and child. After completing this session, participants will be able to distinguish between support and services; demonstrate a strengths-based approach to families; and collaborate effectively with others to provide high-quality early intervention to families and children.

## Objectives

After this session, participants will

1. describe why all high-quality early intervention practices are considered support; contrast support and services; and describe the three types of support that early interventionists should provide families.
2. discuss the importance of focusing on family strengths.
3. describe why a teacher of children with visual impairments (TVI) in early intervention should learn about family members, friends, and other natural supports.
4. demonstrate the completion of an ecomap and describe its advantages.
5. describe how TVIs work in collaboration with other professionals in the early intervention system to provide support to families.

## Major Points

### *Intervention as support*

#### **A. Early intervention as family support**

Early intervention can be described as the provision of support to the family of a child with special needs, rather than as simply the provision of services to the child.

Practitioners in early intervention are in the midst of a paradigm shift. The concept of early intervention primarily as the provision of services to the child is being replaced with a broader concept of support to the family.

Operationally, a service is defined as a specific or particular activity employed by a professional or professional agency to assist an individual or group, such as occupational therapy or special instruction. Generally, but not always, services are the "unit of intervention" used by programs to provide assistance to the children and families served by an agency or program. (Trivette, Dunst, & Deal, 1997, pp. 74-75)

Services are considered to be specific, discrete activities intended to meet specific, discrete needs. Support, on the other hand, implies a more expansive view of providing or coordinating resources to meet a need and may include emotional support, material support, and informational support. These resources may be provided by a specific agency but may also include community resources as well as informal resources available to the family through family and social relationships.

Describing early intervention as simply the provision of professional services is limiting and inaccurate. Doing so suggests that professionals' activities, rather than the family's own actions, account for positive changes in the family and child. Such a description can also lead to the notion, on the part of both professionals and families, that every need requires a specific professional service. In fact, some needs require a more generalized response, such as an existing family support, a normalized community support, or simply a listening ear. Finally, attributing gains to professionals and responding to most needs with services leads to the belief that "more is better" in terms of variety of services and frequency of contacts. The need for a different approach is increasingly being recognized.

I like to use the term *family support* rather than *family services*, because I think many kinds of family support do not require a service but, perhaps, a particular communication style. For example, parents may gain insight into the future needs of their child not only from formal workshops or printed material but also from an offhand comment from a teacher about the expectations of elementary teachers. Thus, we need to start thinking about every interaction with a family being an opportunity for support, as contrasted to discrete and separate services. (Turnbull, 1987, p. 224, as cited in Winton, 1988)

## The Montgomerys

*Although the Montgomerys knew that their daughter Cyndi had been diagnosed with septo-optic dysplasia, they did not understand the connection between the diagnosis and potential concerns related to diabetes insipidus or Cyndi's growth. The TVI was able to share written information about septo-optic dysplasia with the family and also provide information about a Web site for families dealing with this diagnosis. The TVI and the Montgomerys agreed that both would research possible resources, share their findings the following week, and consider the possibility of the TVI accompanying the family on their next clinic appointment. By their next meeting the Montgomerys, having joined a listserv and contacted other parents of children with the same diagnosis, had learned a great deal about their daughter's diagnosis. With this support the Montgomerys now felt comfortable about going to the clinic by themselves and knew they could contact the TVI with possible questions after the visit.*

The example above highlights the provision of informational and emotional support. McWilliam and Scott (2001) identify three types of support that are helpful to families: emotional, material, and informational.

**Emotional support** should be found in the interventionist's interactions with families. McWilliam, Tocci, and Harbin (1998) found that families value professionals who are family centered and emotionally supportive, and that these professionals demonstrate

- *positiveness* about the child and the family.
- *responsiveness*, including taking action when appropriate.
- *orientation* to the whole family, not just to the "client" child.
- *friendliness* (treating the family as you would your neighbor).
- *sensitivity* (walking in the family's shoes).
- *competence* with and about children.
- *competence* with and about communities.

TVIs are often in a position to provide emotional support to families who are overwhelmed when they first receive a medical diagnosis of visual impairment. TVIs know from past experience that these children and families can have happy and successful lives; the TVI can provide valuable encouragement to these families. TVIs also may provide emotional and informational support by helping families understand an ophthalmologist's report and the prognosis in particular. The TVI can help link together families who have children with visual impairments. Families often find this contact mutually beneficial.

**Material support** involves ensuring that family members have adequate resources to meet their physical needs and implement interventions. Providing material support may include facilitating access to equipment, supplies, and information about financial resources, including those pertaining to food (e.g., WIC, food stamps), shelter, and clothing. For example, TVIs may assist families who are eligible for supplemental security income (SSI) in filling out paperwork or talking with SSI advisors. A TVI may provide material support by supplying toys and objects that infants and toddlers with visual impairments typically find appealing. Items such as ladybug and penlight massagers, black-and-white high-contrast toys, and mylar garlands may engage infants and toddlers with visual impairments more than common toys that are commercially available for very young children.

**Informational support** is the provision of information about child development (what comes next, what other children this age are doing), the child's visual condition, resources and services, and activities that will enhance the child's visual function. Many TVIs who are home visitors typically spend most of their time focusing on what to do with the child; they may think of this as teaching the child instead of as providing informational support to the family. When working with the child is seen in the context of support to the family, the TVI who is a regular home visitor knows that the purpose of the home visit is to enhance the capacity of the regular caregiver to implement interventions. The goal is to ensure that families have the confidence and competence to achieve their priorities.

The TVI provides support to a family based on its concerns and priorities, incorporating material, emotional, and informational support specific to the visual impairment while directly addressing the needs of the family. However, families may not be aware of future issues that may affect the child; they may not realize they can facilitate their child's development by using special strategies. Therefore, the TVI should provide information about interventions that address family priorities as well as suggestions for interventions that will enhance the child's development. For example, babies who are blind do not automatically bring their hands to midline but tend to hold them at shoulder height. By placing the infant's hands on a bottle, parents promote midline use of hands, which will later aid in exploration and manipulation of objects. Understanding child development and how visual impairment affects development allows the TVI to provide appropriate informational, emotional, and material supports that are consistent with families' concerns and priorities. While TVIs cannot insist that families include certain interventions, they can, using effective communication techniques, suggest interventions and explain why they are important to the child's development.

TVIs provide support by assisting parents to help their children with visual impairments. Leyser and Heinze (2001) noted several studies that confirm "the experience of caring for a child with a visual disability is often stressful and can be both challenging and threatening to family members" (p. 37). Responses to Leyser and Heinze's questionnaire showed that almost all of the responding parents (96.8%) had concerns about the future of their child

## The LeSeuers

*The LeSeuer family was very concerned about 18-month-old Jolie's lack of interest in moving independently in familiar spaces. Her parents were eager for her to crawl and walk. The family and the TVI could see that Jolie was afraid of moving in space. The TVI also noted a few other areas of concern, such as her reluctance to touch unfamiliar items and textures and her limited interactions with toys and objects in the home. The TVI understood that developmentally Jolie was not ready to begin independent travel, even in the home. Rather than insist that the family abandon their priority of having Jolie move independently, the TVI found ways to work toward independent movement while providing informational support about development. The TVI also provided material support by increasing the types of textures and toys Jolie had at home. The TVI also worked with the family, the orientation and mobility specialist (OMS), and the physical therapist to share information about opportunities for incidental learning that sighted babies have that Jolie lacked. The TVI suggested a variety of strategies to expand Jolie's experiences and readiness for walking. The TVI knew she had made a difference when Jolie's mother exclaimed one day, "Oh, I get it! She really doesn't know that the tile is just as safe for movement as the carpeting! She doesn't even really know when the floor will change back to carpeting!"*

with a visual disability. Additionally, nearly half expressed concern about not receiving information that could help in raising their child, securing resources, meeting other parents, or receiving family counseling. When asked, *What did you find most useful in dealing with your concerns?*, the top three responses were: "actively helping my child," "reading and gathering information," and "having discussions with professionals" (p. 42).

The model of having TVIs use specialized skills and expertise to provide direct services to infants and toddlers with visual impairments is shifting to one in which expertise and knowledge is shared with the family and other team members, enlisting their participation in interventions throughout the week (Correa, Fazzi, & Pogrund, 2002). McWilliam (2000) noted that an early interventionist can usually provide 1 hour of specialized service per week to a child. By sharing the techniques and rationales for interventions with the parents and encouraging them to work with their child throughout the week, the amount of time the child receives support can be increased significantly.

Practitioners acknowledge that some parents are unable or unwilling to participate fully in early intervention with professionals. In these cases, TVIs should be consistent and respectful in inviting parents to be more involved with early intervention but recognize that families have the right to choose their level of involvement.

*Strengths***B. Family and child strengths**

Focusing on the strengths of families and children, rather than on deficits, is a hallmark of effective early intervention support.

Interventionists who implement family-centered practices recognize that family members are the child's primary source of nurturance, lifelong advocates, and key decision makers. Every family is a unique entity, and there are many ways for a family to function effectively. Families set the priorities and identify preferences for their involvement.

In order to implement family-centered support effectively, professionals must look for strengths in families, regardless of their lack of familiarity with the way any given family works. Practitioners should "de-emphasize pathological or negative interpretations of family behavior and focus on greater understanding of how and why families operate as they do" (Winton, 1988, p. 210).

Some family behaviors that could be interpreted negatively may more accurately be viewed as adaptive responses to stressful or negative situations. These behaviors could include

- **"shopping" for a better diagnosis;** the family might actually be trying to confirm or clarify an ambiguous diagnosis.
- **denying the severity of a situation;** at least temporarily, this behavior might serve the family from being overwhelmed and unable to act.
- **choosing to by-pass traditional family activities** such as parent groups; the family might be saving limited energy and resources for activities at home with the child and other siblings (Winton, 1988).

*Family ecology***C. Family ecology**

Understanding the family ecology (i.e., the family's informal supports) is the first step in establishing a working partnership with families, because these relationships are the family's main source of support.

Dunst, Trivette, and Deal (1994) reported that a family's informal supports, their extended family, neighbors, friends, coworkers, and group associations, are more effective than formal supports. Family members spend more time with relatives, friends, and coworkers than they do with the TVI or any other professional, and they already have relationships with these groups. These relationships can provide very effective and efficient support. It is therefore important that the interventionist learn about the family ecology—the system of supports that the family already has. With this information, the interventionist knows about existing support, where duplication of efforts might be avoided, and where there are gaps that need to be filled. Knowing whether a family has an extensive system of support or has just moved to a new geographic area and has very few acquaintances will help TVIs identify the resources that the family already has access to and the level of early intervention support that might be most beneficial.

### Patty, Joe, and Robert

*Patty and Joe are worried and frustrated because doctors have not been able to tell them what caused the medical conditions that their 14-month-old son, Robert, is experiencing. Robert displays delayed development, seizures, cortical visual impairment, small stature, and a variety of other physical anomalies. Robert's parents participate actively on the early intervention team and feel that each specific area of concern with Robert is being addressed. However, because no definitive etiology/cause of these problems has been identified, the parents worry that something is being missed. Also, they don't know what to expect in the future for Robert or themselves. They are planning a trip to a clinic in another city to confer with physicians who may be able to determine the etiology of Robert's multiple impairments. This will be the fifth group of doctors that Robert and his family have seen. Understanding the parents' concern and distress will allow the TVI to offer support, establish rapport, and continue to provide VI-specific support to Robert and the family.*

If family members are interested in talking about the family, the initial intake visit is the preferred time to learn about the family's existing relationships and natural system of support. Cultural issues, the family's immediate needs, length of time to complete other intake procedures, and the family's comfort level about sharing personal information are all factors to consider when asking about a family's ecology. If the family seems reluctant to discuss personal information, it is best to postpone the discussion of the family ecology until trust and rapport have been established.

In addition to assessing the family ecology, other purposes of the intake visit include

- conveying information about the program or supports that are available to the family.
- determining the family's primary concerns.
- establishing rapport with the family.
- securing permission to conduct assessments and to inform family members of their rights.

There are several ways to gather information about a family that will best help the interventionist in providing support. Interviews and questionnaires are frequently used to learn about a family. Simply observing the family in action is another way to gain information. Community resource mapping is the compilation of a list of resources available to a family and the physical location of these resources (Trivette, Dunst, & Deal, 1997). Another useful tool is the ecomap, produced during an informal dialogue between the interventionist and family members. The importance of understanding the family ecology and the development of an ecomap are described in the

flyer "Understanding the Family Ecology" (McWilliam, 2001) in this session (Handout A).

In many states the TVI will not be a part of the early intervention team at the time of the intake visit. When the TVI joins the team, he or she can ask the service coordinator if an ecomap has been completed. If not, the TVI can describe an ecomap and its purpose and ask the family if they are willing to participate in the process with the TVI. The TVI will, of course, share the information with all team members.

### *Ecomaps*

#### **D. Ecomaps**

An ecomap is a graphic portrayal of the family, including the family's informal supports, formal supports, and intermediate supports.

The primary purpose of the ecomap is to provide a visual depiction of a family's relationships. An ecomap may be the most efficient way to depict the various relationships that comprise a family's ecology. It is important for families and professionals to understand that the goal of providing overall family support, rather than simply providing child-related services, drives the information gathering process of the ecomap. The ecomap has been used extensively in other areas of social services to map the family ecology and identify potential and existing supports and resources.

While the visual depiction of the family's system of supports is useful in its comprehensiveness, the process of developing the ecomap is also important. This can be an opportunity to establish rapport and demonstrate an interest in the family. Professionals should use empathetic interviewing skills to develop the ecomap properly. Without effective interviewing skills, the ecomap becomes another bureaucratic exercise that neither professionals nor families like. When done correctly, however, families are very positive about the experience. Furthermore, the ecomap can be completed in 15 minutes, so it is not difficult to incorporate into the home visit. The process of developing an ecomap is as important as the final product.

The following guidelines for developing an ecomap were adapted from "Understanding the Family Ecology" by R.A. McWilliam (2001). (Please see Handout A.)

1. Introduce the ecomap and its purpose.
2. In the middle of an 8½ x 11 sheet of paper, write the names of parents/caretakers, the child and siblings, and anyone else who lives in the home. Draw a box around those people.
3. In the space above the family, draw boxes labeled with the family's sources of informal support, such as extended family, friends, and neighbors. Write the name(s) of each source of support.
4. Gain information about these possible sources of informal support by asking questions like, "Did you grow up in this town? Where are your parents? Do you often talk to them?" Other questions that you

might ask include: "Where are . . . ? How often do you talk to . . . ? And then what? Tell me about your friends. Who else can you count on?" Ask questions that provide information about the support the family receives.

5. Do not ask questions such as: "Who's your husband? Are you married?"
6. Draw lines from the boxes to the family box, using wide double lines to demonstrate more support, single lines for less support. Dotted lines indicate stress. A family can receive a great amount of support from a source and also feel stress.
7. In the space below the family, draw boxes for the formal supports the family receives, such as other early intervention services, medical services, daycare, and financial support (including insurance) as appropriate.
8. Use the spaces on the sides of the family's box to record intermediate supports such as people at work or places of worship.
9. Make eye contact (if culturally appropriate), show interest, and find out about sources of support for the family. Be sensitive to the family's level of comfort.
10. Conclude each area of support by asking, "Are there any other relatives, friends, or people that should be in this picture? Is there anything else we should add?"
11. Conclude the ecomap session by saying, "Thank you very much. This will be very helpful in my understanding of who you already have for different levels of support in your life. This will help me make suggestions and provide information that is relevant to your life."
12. Do NOT judge.

## E. TVIs

## TVIs

The TVI works in collaboration with other professionals in the early intervention system to provide support to families and the child with a visual impairment.

A visual impairment affects all areas of growth and development of the child and affects interactions between the child, family members, and caregivers (Bishop, 2000; Ferrell, 2000). Families and other professionals on the team may not understand the important implications of this fact because they may have no prior experience with visual impairments. A primary responsibility of the TVI is to provide family-centered support while ensuring, through collaboration with members of the early intervention team, that the impact of visual impairment on child development is recognized and addressed by each team member. When TVIs collaborate with other team members, they not only share vision-related information and resources through consultation, but also assist other team members in understanding issues related to vision and development. This is an example of role release and is reciprocal, as TVIs learn about other disciplines in the same manner from other team

members (Correa et al., 2002). This type of collaboration is a key feature of the transdisciplinary model, which provides a holistic approach to family support. (Please see Session 2 for additional information on team models.)

### References for Major Points

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## **Instructor Resources**

### **Major Points**

- See pp. 185–194.
- The information in the Major Points is abstracted in the tutorial found in the second and third tabs of the Session Content section of the Session 3 interactive multimedia CDs, both Instructor Version and Participant Version.
- The Major Points can be found in document form in the Session Content section, Resources tab, under “Session Notes,” of the Session 3 interactive multimedia CDs, both Instructor Version and Participant Version.
- They can also be found in the Participant Resources section of the Session 3 interactive multimedia CDs, both Instructor Version and Participant Version.

### **Instructional Sequence**

- See pp. 199–200.
- The Instructional Sequence can also be found in the Resources for Instructors section of the Session 3 interactive multimedia CD, Instructor Version only.

### **PowerPoints**

- See the reproduction of the PowerPoint slides on pp. 201–213.
- The PowerPoint slides can be found on the Session 3 video CD.
- They can also be found on the Session 3 interactive multimedia CDs, both Instructor Version and Participant Version, in the Instructor Resources and Participant Resources sections.