

Module: **Family-Centered Practices
for Infants and Toddlers With Visual Impairments**

Session 1: Building Reliable Alliances

Activity E: Interdisciplinary Panel

Instructor Guidelines

The purposes of this activity are for participants to

- meet real life early intervention professionals who work in a variety of community settings in the context of a panel,
- describe to a parent the various roles and responsibilities that a specialist who serves young children with visual impairments and other early intervention professionals have in providing early intervention services, and
- recognize the various contexts within which early intervention takes place.

Time needed. 1 1/2 hours minimum

Materials included. Vignette, instructor's ecomap guidelines, a sample letter to interdisciplinary panel members, and a sample thank-you letter to interdisciplinary panel members

Prepanel planning. The instructor should identify and invite five or six early intervention professionals, including a specialist for children with visual impairments, to serve on the panel. Invite professionals from a variety of disciplines and agencies who have a good reputation for their sensitivity in working with families. It also is important to invite a parent of a young child with a visual impairment to be on the panel to react to and discuss the presentations. (See sample letter of invitation with instructions to panelists and sample vignette.) It is best to make phone or personal contact first to get their agreement and describe the process before sending the letter.

Before this activity, make sure all panelists feel secure and comfortable in their roles. Ask if they have questions about the vignette. You could ask everyone to meet you 15–20 minutes before the class starts for this discussion. If that is not possible, try to talk to each panelist individually to see if they have questions. The role of the parent on the panel is to reflect on his or her own experience in the early intervention system, especially in context of everything he or she has heard the panelists say. Clarify time limits so no one dominates the allotted time.

Make table tents for panelists with their names in big, bold letters. Prepare a table at the front of the classroom where the panelists can sit with their table tents in front of them. Think about the best order of presentation in terms of content and process and arrange

table tents to reflect that order. Make signs to tell panelists when they need to stop speaking. Show signs to panelists in advance so everyone is reminded about the time limits on speaking.

Set up a flip chart in the front of the classroom in a spot that can be seen by participants and panelists. Draw an inner circle with a child and family symbol in it.

Panel format. The instructor introduces the panel as a whole, but lets each panelist give his/her own introduction as part of his/her presentation. The instructor tells everyone that as the panelists speak, the instructor will be creating an ecomap on the flip chart that illustrates the various contexts and environments in which early intervention takes place in the community. (Please see background information on ecomaps in Session 3). Participants are instructed to take notes and make a list of questions they want to ask. They also are encouraged to jot down ideas for their philosophy statement project as they listen to the panelists speak.

Each panelist has 5 to 7 minutes to address the two or three questions about the vignette they have been given in advance. As each panelist presents, the instructor writes the setting in which they work and the discipline of the panelist on the ecomap.

By introducing the parent on the panel, the instructor can call attention back to the center of the ecomap. The family member usually describes how overwhelmed she or he feels just listening to all the different panelists speak about their services and programs and might reflect on how overwhelming the system really is.

Panel debriefing and discussion. The instructor thanks the panelists for their presentations and invites participants to ask questions. Questions that often are asked include the following:

- Do the panelists ever work together? (Often they have heard of each other but have never met. This is a good dose of reality for the participants who realize that coordination is a big challenge.)
- Who pays for the services? (This is a great question because there is no easy answer, and it forces everyone to acknowledge how confusing the system is for families.)
- How do families find out about all these different programs and services? (Family members often say “from other families” which is eye-opening to participants.)
- If they moved to a new community as an entry level professional, how would they find out about all of these different clinics, agencies, etc.?

Postpanel follow-up. After panelists leave, it is important to give participants a chance to do some further debriefing about the experience. They may want to question something that was said, or ask questions that they were hesitant to ask in front of the panelists. This is an excellent time for participants to do some work on their philosophy statement project. The instructor may want to send a thank-you note to panelists.

Vignette: Sam

Referral information:

Child's Name: Samuel "Sam" Cummings

Child's Age: 18 months

Mother's Name: Sarah Cummings

Mother's Occupation: Apartment Manager

Father's Name: Calvin Cummings

Father's Occupation: Operating Room Technician

Sam is Sarah and Calvin Cummings's second child. They have a 3-year-old daughter, Christa, who was born four weeks early. Christa appears to be developmentally normal but has chronic middle ear infections, reactive airway disease (RAD), and incipient asthma. Sam was born eight weeks early (32 weeks gestation) and weighed 5 lbs. 8 oz. at birth. He was noted to have Pierre-Robin Sequence (a triad of clinical findings triggered by the primary defect of mandibular hypoplasia, or small lower jaw, and accompanied by the secondary defects of glossotosis, or retroplated tongue occluding the airway, and isolated cleft palate) and congenital cataracts. Sam would turn blue if reclined or even placed on his side because of the small jaw and retropositioned tongue. He would also stop breathing if given liquid by mouth. He remained in the hospital for the first five weeks. He had to remain on his tummy with his head and shoulders elevated over a soft roll. The tip of his tongue was sutured to his chin to open up the airway, and he was fed via nasogastric tube. At three weeks of age, he had eye surgery to remove the cataracts. He gained weight slowly and continued to be generally hypotonic, complicated by his positioning and mobility limitations.

When discharged home at 5 weeks of age, Sam weighed only 6 pounds (4 ounces greater than his birthweight). He still had to remain on his tummy or be tilted forward much of the time and continued to be tube fed. His parents were both trained in CPR, management of oxygen, operation of an oximetry monitor (which Sam had to be attached to when sleeping or eating), and nasogastric tube feedings and management (i.e., removing and replacing tubes). At 8 weeks, Sam developed severe upper respiratory and bilateral ear infections. He responded to antibiotic treatment but regurgitated several feedings, became dehydrated, and lethargic, and had to return to the hospital for 2 weeks. At 3 months of age, Sam began to breathe more easily regardless of his position and the tongue-tip sutures were removed. He continued to require tube feedings until 10 months of age when his isolated cleft palate was repaired. After his palate surgery, Sarah was able to feed him slowly by cup, and he began taking some foods by spoon. Sam has had two or three more bouts of ear infections, and he is very difficult to feed when he is congested. Recently Sarah has become concerned about Sam's vision, his lack of speech, and his "lack of interest in moving around."

Sam was referred to the early intervention program by his pediatrician, Dr. Bob Bishop, at the hospital's Special Infant Care Clinic (SICC). The clinic is only able to follow high risk infants for the first 18 months of life. His general care will be transferred to the outpatient pediatric clinic, but Dr. Stanton is concerned about Sam's continued

slow weight gain, generalized low muscle tone, and global developmental delays. Dr. Stanton has also referred Sam for a follow-up eye exam. Sam was evaluated at 12 months by a physical therapist at the SICC who gave Sarah some exercises to do at home. Sam has not had any other formal developmental assessments.

Written by Penny Merritt, Child Development Unit, Department of Pediatrics, Duke University Medical Center. Previously unpublished.

Developing a Community Ecomap

The purpose of drawing an ecomap as part of the interdisciplinary panel activity is to

- illustrate all of the different places and contexts where early intervention takes place in the community and
- provide a rationale for why collaboration and coordination are important parts of the early intervention process.

Materials. White board, chalkboard, or flip chart with markers

As part of the introduction of the panel, the instructor can show Power-Point slide 11 of Bronfenbrenner's ecological framework and tell the participants that they are going to have the opportunity to learn more about the second concentric circle of the model labeled *community*.

The instructor could mention that in another session the participants will be introduced to a family ecomap to illustrate the family component of the ecological model.

The instructor will draw on the chalkboard or flip chart paper the inner circle of the ecological model with the child and family written within the circle. As each member of the interdisciplinary panel tells where he or she works, the instructor writes the name of that particular agency/institution/organization somewhere outside the inner circle. The instructor then continues to add names of agencies as each panel member takes her or his turn.

The instructor asks the parent on the panel about additional supports and resources that may not have been represented by the panel. Then the instructor adds these resources to the ecomap.

Sample Letter to Interdisciplinary Panel Members

Date

Dear Colleagues:

Thank you very much for agreeing to help with our Family-Centered, Interdisciplinary Approach to Early Intervention course by participating as a panelist and discussant. Enclosed are the objectives for this session, as well as a brief case vignette. I hope the panel will help achieve the class objectives in an interesting and lively way. I will ask each panelist to address the following questions related to the vignette:

1. In what early intervention context would you be likely to come into contact with this family?
2. What kinds of additional information would you be interested in gathering about the son and his family?
3. How might you be involved in intervention with the child and his family?

In order to maintain a crisp pace, I suggest a somewhat concise response to these questions at first (perhaps 5 minutes). I hope this will lead to a discussion about the need for collaboration among disciplines and strategies and considerations related to teaming. There will be other panelists representing different disciplines including families.

As we mentioned in the phone call, this event is planned for ____ (date). The class will meet from ____ to ____ (time) in the ____ (location). Directions are enclosed. The panel will start at ____ (time) and end at ____ (time). I hope you will stay for as much of the discussion after the panel as you can.

Thank you again for your help. Please call me at _____ or email me at _____ if you have any questions or concerns.

Sincerely,

Date

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Thank you again for your help. Please call me at _____ or email me at _____ if you have any questions or concerns.

Sincerely,

Sample Thank-You to Panel Members

Date

Dear Colleagues:

Thank you so much for giving a “face” and some life to the key early intervention disciplines. That “face” was one of competence, sensitivity, and all of the qualities that the class is trying to promote and encourage. You also helped paint a very realistic picture of our “community-based system of care” which is imperfect and evolving.

Thank you again for taking time out of your incredibly busy lives to share your expertise and provide a wonderful role model for the students. We really appreciate it. Please call us if we can repay the favor in any way.

Sincerely,

P.S. Would you like a copy of this letter sent to anyone—your boss? Supervisor? We would like to share your contribution with others if that would be appropriate. Let us know.

Date

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