

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

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**Session 1: Building Reliable Alliances**

**Activity C: Family Philosophy Project**

**Participant Guidelines**

The purpose of this project is to develop a philosophy statement about family-centered care and intervention, based on listening to parents, readings, feedback from instructor and peers, and course activities.

**Participant Outcome.** To be able to describe to a parent your overall philosophy for working with families, including the basic assumptions and principles that guide your approach.

**Format.** This is an ongoing project that will culminate in each participant having a unique statement of principles or assumptions that will guide their work with children and families. You will begin this project during the first class session. The project will conclude with a copy of your philosophy statement being turned into the instructor on \_\_\_\_\_.

The philosophy statement will be developed, refined, revised, and shaped as a result of the readings, discussions, presentations, and reflections throughout the semester of the course.

**Please bring your philosophy statement with you to all classes.** Because we are interested in the evolving nature of each participant's philosophy statement, we ask that you share your draft of the statement with the changes, additions, and draft comments on \_\_\_\_\_.

In addition to your philosophy statement, we are interested in your reflections on challenges that you observe in the field that will make it difficult for you to engage in family-centered practices. These reflections should incorporate your philosophical beliefs. We are also interested in "pockets of excellence" or exemplary programs or individuals that you feel reflect your philosophical beliefs about working with families. We would like you to share that information with us in a reflection paper that is turned in on \_\_\_\_\_.

**Final Products.** The final version of the philosophy statement should be rendered in a format that would be suitable for framing or mounting on an office wall in a future workplace. The reflection paper should be brief (one page) and typed.

Draft statement due: \_\_\_\_\_

Final version due: \_\_\_\_\_

## **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 3 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.*