

**Module: Visual Conditions and Functional Vision:
Early Intervention Issues**

Session 3: Visual Conditions in Infants and Toddlers

Handout N: Visual Conditions Vignettes, Session 3

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Trista

For the past 6 years, Trista has worked as a TVI with her local early intervention agency. When she first began, she had a caseload of three children who all had retinopathy of prematurity. Today she supports sixteen families of young children with visual impairments or blindness. Her caseload includes children with cortical visual impairment, retinopathy of prematurity, optic nerve hypoplasia, Leber's congenital amaurosis, high myopia, and albinism.

Recently Trista was asked to support other local TVIs in an effort to develop child find activities. She reflected back to when she first began her work in early intervention. In order to increase her caseload and meet the needs of children in her area, she had informed people about the program, helped others understand the leading causes of visual impairment in young children, and built trusting relationships with other local programs, NICUs, therapists, ophthalmologists, pediatricians, and Part C coordinators. As Trista worked with other TVIs, she shared ways to collaborate with professionals in order to increase referral rates, thereby increasing the number of children identified with visual impairments in their area.

Shanu and Tamul

Six-month-old twins Shanu and Tamul were born at 25 weeks' gestation. Their early interventionist recently submitted a referral to Laurence, a local TVI, for support and services. Laurence briefly reviewed the referral. He learned that Shanu has bilateral retinal detachment due to Stage 5 ROP and uses a feeding tube and oxygen for most of the day. Tamul has Stage 3 ROP.

When Laurence spoke with the early interventionist, he learned that their mother is very hesitant to have people in the home because the twins are frequently ill and are still medically fragile. He also learned that their mother does not allow other people to handle the twins unless they are sign and symptom free from colds and other illnesses, and then only after they have thoroughly washed their hands. Given their mother's concern for the health of her children, Laurence knew that he would need to work closely with the intervention team in order to meet the family's needs.

Katrien

Katrien, a 14-month-old with Stage 3 ROP, sat on the lap of her foster mother, Layla, during an exam with the ophthalmologist. Based on his exam, the ophthalmologist felt that Katrien ought to be more visually attentive. During the exam, Layla commented on the fact that even when Katrien wears her glasses, she does not attend visually to people or objects in her environment. When the ophthalmologist questioned her further, he heard familiar comments such as “Katrien never looks at me when I talk to her” and “Sometimes I feel like her vision is different every day.” After completing the clinical exam, reviewing her complicated medical and birth history, and hearing the family’s concerns, the ophthalmologist and Layla agreed to have Katrien further evaluated for a diagnosis of cortical visual impairment.

Dallas

Felix, the occupational therapist, was eager to meet with Carson, the TVI, and the Romane family. The Romane family had expressed interest in making independent feeding a goal for their son, Dallas. Dallas has cortical visual impairment and mild ataxic cerebral palsy. Felix felt comfortable in assisting the family in creating adaptations for the motor components for feeding goals, but he knew that Carson could help them in facilitating Dallas’s optimal use of vision during mealtime.

During the meeting, Carson discussed the results of Dallas’s latest functional vision assessment (FVA). Based on the FVA, they knew that Dallas responds well to the color purple and that he tends to use his right eye for central fixation and viewing. He also has difficulty with clutter and noisy environments. In order to facilitate Dallas’s feeding goals, the family decided to begin their dinner routine with the television off to reduce noise. Additionally, they decided to use a purple sippy cup placed on the right side of the highchair tray. The family also moved Dallas’s highchair so that it faced the white kitchen wall rather than the open family room. This would assist in decreasing the clutter in the background. Within a few weeks the family noticed that Dallas was much more visually attentive during meal times and was showing progress in independently using his sippy cup during these routines.

Piper

Adonia and Jared sat quietly next to the incubator in the neonatal intensive care unit. Piper, their daughter, was born at 25 weeks’ gestation and weighed 1 pound, 2 ounces. It had been quite an ordeal in the NICU—she had surgery for her eyes and her heart, and she experienced occasional seizures.

Piper now weighed just over 5 pounds and would be going home soon. Even though Adonia and Jared were excited about finally taking their baby home, they were nervous. Piper would still need oxygen at night, she would have to see multiple specialists for continuous follow-up, and they were just beginning to understand the impact of her visual impairment. The ophthalmologist in the NICU had explained that Piper had stage 4 retinopathy of prematurity.

At first, Adonia and Jared worried that treating their baby with oxygen had

caused her visual impairment. The doctor reassured them that this was not the case, because the retina usually does not finish developing until a baby is about 32 weeks' gestation and continues through final development even after babies are born. Because Piper was born early and had developed Stage 4 retinopathy of prematurity, the retina had begun to pull away from the back of her eye. The doctors had completed surgery to help save the retina and improve Piper's vision. The doctor called the surgery successful, but Adonia and Jared realized that they would not fully understand how and what Piper could see until she was home.

Damon

Damon crawled across the floor to his mother, Linda. She scooped him into her arms and kissed him on the cheek as she walked him into the kitchen. Linda remembered how she used to dread this part of the morning. It was time for Damon's medications, and in the past he had always resisted when it was time to take them.

Damon was born with optic nerve hypoplasia (ONH) and was diagnosed at 2 months with septo-optic dysplasia (SOD). He now takes growth hormones and medication for diabetes insipidus. Linda is especially thankful for the support she receives from Damon's TVI, Lynn. Lynn has provided the family with information so that they can understand Damon's diagnosis, visual abilities, and development. Also, she introduced Linda to other families that have children with ONH and SOD. Talking with other moms, Linda learned helpful tips on how they administer medications to their children. With these ideas, Linda has learned how to make this time of the day a positive experience.

Dajah

Dajah was born at full term without complications to a mother with a typical and healthy pregnancy. Before Dajah left the hospital, she was diagnosed with anophthalmia in her left eye and colobomas of the iris, choroid, and retina in her right eye. The hospital where Dajah was born immediately referred the family to the local division of services for the blind.

When Dajah was 6 weeks old, the family met with a social worker and a TVI who helped the family understand these two specific visual conditions. The family had fears and concerns about how their daughter would appear to others because she had only one eye. The TVI and social worker explained to the family that they could find an ophthalmologist who would refer them to an ocularist to fit Dajah with a conformer until she was old enough for a prosthetic eye. The TVI explained that colobomas are like having holes in those parts of her eye. The family now understands that colobomas result from failure of parts of the eye to fully develop within the first few weeks of pregnancy. Additionally, the TVI discussed how she could come to their home and support the family in understanding Dajah's visual abilities and make suggestions for adaptations, when necessary, to facilitate Dajah's optimal use of vision as she develops.

Ross

Wayne and Gail planned a picnic at the park for their family. Their youngest son, Ross, has oculocutaneous albinism like his father. Before leaving, Gail made sure to pack Ross's sun visor and sunglasses. Their last trip to the park had not been much fun for Ross because his sun visor had been left at home. Ross was unable to play with his siblings in the grass because the sun was too bright, and he could not open his eyes fully. Gail also made sure that Ross had a lightweight, long-sleeved shirt to cover his sensitive skin. The last thing she packed was a yellow-and-black soccer ball. The ball provides sufficient contrast so that Ross can chase the ball with his siblings.

Jaedon

Jaedon rested peacefully in her father's arms. She was born with bilateral posterior cataracts, a condition inherited from the maternal side of her family. She had undergone surgery the day before to remove the cataracts. The doctor explained that Jaedon's cataracts were near the back of the lenses and were large and very dense, with the potential to cause significant visual impairment if they were not removed. Jaedon is 3 months old and will now wear aphakic glasses to compensate for the lenses that were removed from her eyes. These glasses will help Jaedon focus on objects at close range.

Klyde

"Come here, my little sweet potato," called Selia. She walked toward her toddler, Klyde, who was smiling as he scooted away from her. He had once again pulled his glasses from his face and was moving away from his mother. Without his glasses, Klyde's left eye turned in toward his nose. When he was about 6 months old, Selia noticed that Klyde's right eye appeared to turn out, and she mentioned it to her pediatrician, who recommended a visit to the ophthalmologist. The ophthalmologist said that Klyde had exophoria. Selia thought at first that Klyde was too young for glasses, but the ophthalmologist reassured her that wearing glasses now would help prevent amblyopia, which could occur if Klyde continued to be unable to use his right eye efficiently. Even though it was difficult persuading him to keep his glasses on, Selia knew that treatment was critical to assure that Klyde could see clearly and to prevent delays in his development.

Levi

Darby, the TVI, arrived at Levi's IFSP meeting with brochures about childhood glaucoma. Levi had previously been diagnosed with glaucoma and strabismus, and the team, including the family, had made great progress in facilitating Levi's development. Darby wanted to make sure that each team member knew the basic facts about glaucoma, including signs and symptoms of increased pressure in Levi's eyes. Darby knew that if all the team members were aware of such symptoms, they would be better prepared to prevent further damage to Levi's eyes that could lead to serious visual impairment or even blindness. Darby also wanted to discuss the importance of continuing to monitor Levi's use of vision to determine environmental modifications.

Glaucoma in addition to strabismus could have further implications for the types of lighting needed and the contrast used in the materials found in his daily routines.

Quinn

Perry, the TVI, was observing 6-month-old Quinn, who has optic nerve hypoplasia. Perry had worked with Quinn for about 3 weeks and was completing Quinn's functional vision assessment. As Perry held Quinn in his lap and spoke quietly to him, he observed that Quinn had nystagmus. As he continued to talk and play babbling games with Quinn, he noticed that Quinn would turn his head slightly to the left and downward. Perry made note of this null point on his assessment sheet, drawing Quinn's eyes and marking the position of his null point. Perry also recorded that the nystagmus was conjugate (both eyes), pendular (equal speed and directions), and horizontal. He described this to Quinn's mother as Quinn's eyes moved together horizontally in equal speeds and directions. He also explained that the null point refers to the place where the nystagmus slows and where Quinn is able to optimize his vision.