

Visual Conditions and Functional Vision: Early Intervention Issues

Session 1

Working With Families and Eye Care Professionals

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Module: **Visual Conditions and Functional Vision:
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Introduction

Welcome to Session 1, “Working With Families and Eye Care Professionals,” of the *Visual Conditions and Functional Vision: Early Intervention Issues* module. In this session, participants will acquire knowledge and skills that will enable them to work collaboratively with families, eye care specialists, and early intervention team members. In addition, participants will identify roles of various eye care specialists and learn how to support and prepare families for their interactions with eye care specialists.

Objectives

After completing this session, participants will

1. compare and contrast the roles of different eye care professionals.
2. describe the components of an eye care examination and information families should expect to receive following the exam.
3. describe strategies that early childhood vision consultants (ECVCs) use to support families who seek to understand their children’s visual diagnoses.
4. discuss factors such as learning styles and language and cultural barriers that affect families’ abilities to access and understand information and describe strategies for providing support to overcome these barriers.
5. describe strategies for facilitating interactions and communication between eye care specialists and families.

6. describe the role of TVIs when working with eye care specialists and other professionals using the transdisciplinary model.

Major Points

A. Eye care professionals

There are several types of eye care professionals, each having different responsibilities and training. Table 1 provides some basic information about these professionals. This information is also in Handout A. Teachers of children with visual impairments should assist families and other members of the early intervention team in understanding the roles of the different types of professionals.

Table 1. Eye Care Professionals

Eye Care Professionals	What they do	Training
Ophthalmologists (MD)	Perform surgery Diagnose and treat eye diseases Test for visual acuity and visual field Prescribe glasses and contacts, and in some cases, low vision devices and medication	4 years college 4 years medical school 1 year general medical internship with a choice in pediatrics, internal medicine, or general surgery 3 years ophthalmology residency 1 to 2 year fellowship for subspecialty of pediatric ophthalmology
Optometrists (OD)	Diagnose vision problems and prescribe glasses and contact lenses. May work with ophthalmologists to provide pre- and post-operative care May conduct low vision exams and provide vision-training activities if a specialist in low vision Some states allow optometrists to prescribe medication. Some optometrists may practice behavioral optometry.	4 years of college 3-4 years optometry school (1 year may be an externship)

Eye Care Professionals	What they do	Training
Low vision specialists	<p>Test for visual acuity and visual field</p> <p>Introduce patient to near and/or distance viewing low vision aids</p> <p>Recommend adaptations to patients' home and work environments</p>	<p>Low vision specialists may be licensed ophthalmologists or optometrists with credentials as diplomates or certified low vision specialists.</p> <p>Certified low vision specialists may be educators with certification from either the Academy for Certification of Vision Rehabilitation and Education Professionals or the PA College of Optometry</p>
Orthoptists	<p>Evaluate and treat disorders of vision, eye movements, and eye alignment in children and adults</p> <p>Conduct diagnostic tests on patients with visual disorders, including amblyopia (lazy eye), strabismus (misaligned eyes), and double vision</p> <p>Help the ophthalmologist design a treatment plan, which may involve treatment by the orthoptist, surgical treatment by the ophthalmologist, or some combination of the two</p>	<p>Orthoptist programs are 2 years.</p> <p>A baccalaureate degree is required; however, admission criteria vary from school to school and exceptions are considered on an individual basis.</p> <p>In most programs, preparation and presentation of a scientific paper is usually required during the second year of education.</p> <p>Extensive clinical experience is part of every program.</p>
Opticians	Grind and fit lenses prescribed by the ophthalmologist or optometrist	<p>1 year of optical courses</p> <p>2 years apprenticeship under certified optician</p>
Ocularists	Design and fit artificial eyes (prostheses) and scleral shells	<p>Requires board certification</p> <p>Candidate takes exam through the National Examining Board of Ocularists.</p>

Typically, an **ophthalmologist** initially sees most children with severe visual impairments for diagnosis and treatment. In addition to prescribing glasses, contact lenses, or treating strabismus or amblyopia with occlusion (patching), the

ophthalmologist can perform surgery and prescribe medications if needed. The ophthalmologist will also recommend a follow-up treatment plan. The follow-up plan and intervals between follow-up eye examinations will depend upon the child's diagnosis and prognosis—whether or not the visual condition is stable or progressive, or if a definitive diagnosis has yet to be determined. While most general ophthalmologists diagnose and treat the most common visual impairments, they may refer younger infants or those with relatively uncommon visual impairments to pediatric ophthalmologists. Pediatric ophthalmologists, ophthalmologists who work primarily with children, have expertise in assessing very young children and more familiarity with a variety of supports and services. In some situations, pediatric ophthalmologists may refer families to another eye care professional, such as a retina specialist or a neuro-ophthalmologist if more information is needed about the visual condition.

The **optometrist** is a doctor who performs refractions, completes eye health tests, and prescribes glasses, contact lenses, and occlusion for amblyopia or strabismus but who does not perform surgery. The optometrist performs many of the same procedures as the ophthalmologist with the exception of surgery. In some states, the optometrist can prescribe medication. In some cases optometrists may also practice behavioral optometry.

Some ophthalmologists and optometrists may specialize in assisting people with low vision to maximize use of vision so they have greater daily independence. In addition to their medical training, these **low vision specialists** receive training in the use of low vision devices and other assistive technology and prescribe optical devices to help individuals accomplish visual activities more efficiently.

Although ophthalmologists and optometrists may specialize in low vision and have credentials in this area, some educators may also be certified as low vision specialists. These individuals may be certified by either the Academy for Certification of Vision Rehabilitation and Education Professionals or the Pennsylvania College of Optometry. The Pennsylvania College of Optometry also offers a master's degree in low vision rehabilitation.

Behavioral optometrists assess visual processing of their patients and incorporate vision therapy and behavioral vision care into their practices. Sometimes, parents will hear about this service and ask the TVI if their child would benefit. Although some case studies indicate positive outcomes, the clinical and research literature do not conclusively support these methods. TVIs are not qualified to provide this type of treatment. Instead, when asked about behavioral optometrists, TVIs should provide families with unbiased information and then allow families to make their own decisions.

The **orthoptist** implements programs prescribed by an eye care specialist and often serves as a liaison between eye care specialists and parents regarding treatment for

strabismus and other eye alignment conditions. Although orthoptists are usually affiliated with teaching hospitals, it may be worth asking if a certified orthoptist is available to assist with a treatment plan when appropriate. Orthoptists may be particularly helpful for children with strabismus because they typically specialize in eye movement and alignment and are able to monitor treatment for strabismus and/or amblyopia.

Opticians are licensed to dispense eyeglasses and contact lenses as prescribed by the ophthalmologist or optometrist. Opticians measure the distance between the pupils and suggest frames so that the glasses fit a child's face comfortably and correctly. There are many options for eyeglass frames. The caregiver should carefully check that the frames do not slide down the nose of the child and that there are no red marks behind the child's ears. If the child does not tolerate wearing the glasses when they are first prescribed, the optician is the first person the caregiver should consult when checking the accuracy of the prescription and fit of the frame.

Ocularists are technicians who are trained to fit, shape, and paint ocular prostheses. They also teach patients to handle and care for prostheses and perform periodic examinations. Ocularists may be involved in treatment for children with anophthalmia or possibly retinoblastoma (if eyes must be enucleated).

B. Components of the clinical eye exam

There are several reasons to ensure that children have as thorough and comprehensive an eye examination as possible and that they attend follow-up appointments over time. It is important to monitor the health of the eyes, especially if the condition is progressive or has the possibility of developing complications. It is also important to measure refractive errors. If the refraction error can be corrected, the ophthalmologist or optometrist can write a prescription for glasses so that the child will see as clearly as possible. In addition, low vision devices may need to be prescribed or changed (Stiles & Knox, 1996).

Understanding how and why procedures are performed may ease some family members' anxiety about what will happen in the eye care specialist's office.

- The ophthalmologist or optometrist will perform a complete eye examination. Infants and young children who are not verbal can be examined, and a great deal can be learned about their eye condition even without verbal responses. The doctor who is patient and spends sufficient time with the child will be more likely to secure the best medical information possible (Buckley, 2003). In rare cases, the doctor may discuss with the parents the need to medicate the child or use anesthesia to put the child to sleep in order to fully evaluate the eyes (Allen, 2000). The acronym *EUA* (exam

under anesthesia) may be used in reports to indicate that the exam took place under anesthesia.

- During the visit to the eye care professional's office, the doctor or an assistant will gather a complete medical history of the child and family, including whether other family members have the same visual condition. Because the eyes begin developing during the early stages of fetal development, the eye care specialist will ask questions about the mother's pregnancy and the method of delivery. Such questions may include whether there were any unusual events during the first three months that may be linked to the visual impairment of the child, what medications the mother took, or whether she had any infections, especially during the first trimester. Other topics that may be discussed during the history interview include the child's current symptoms and reason for the visit, current medications and allergies, and the parents' description of the child's visual abilities (Buckley, 2003; Stout, 2003). The information obtained during the history interview can help the doctor make an accurate diagnosis.
- The eye care professional will observe the external appearance of the child's face and eyes and how the child holds his head.
- The eye care professional will measure the child's visual acuity (the ability to discern detail). During this assessment, the doctor will typically evaluate fixation and eye movements (Wagner, 1998). The method that the eye care specialist selects will depend upon the child's age, ability, and willingness to respond (Buckley, 2003; Stout, 2003). Both near and distance visual function should be assessed (Buckley, 2003).
- An infant's pupils will react normally to light by approximately three months of age (Allen, 2000). When assessing a child's pupillary response, the eye care specialist will shine a light into or slightly above the child's eyes and note whether the pupil briefly constricts and whether the constriction is brisk or sluggish. Eye care professionals can often use variations in pupillary responses to help make diagnoses (Buckley, 2003).
- An infant's visual field continues to mature after birth (Allen, 2000; Mohan & Dobson, 2000). When assessing visual fields, the doctor will first direct the young child's attention to a centrally located toy or object while introducing a second toy quietly from the periphery. If the child's eyes move toward the toy in the periphery, it suggests that a particular visual field is intact. This method depends upon the doctor's ability to follow the child's eye gaze and detect fixation and may be difficult to perform in very young children (Buckley, 2003).
- Many eye care professionals do not attempt to measure color perception in infants and toddlers. According to Stout (2003), pseudoisochromatic color plates can be used to screen for color vision defects in children who have cognitive and fine motor abilities in the 3- to 4-year-old range.
- The eye care professional will dilate the pupils by putting drops into the child's eyes. The interior of the eye can then be examined with an indirect ophthalmoscope

(Wagner, 1998), a head-mounted light used with special hand-held lenses. During this part of the exam, the doctor can look at the lens, retina, and optic nerve. Handout B provides a diagram of the eye that the TVI may share with the family during this part of the exam.

- An eye care professional can determine if a child needs glasses or appropriate corrective lenses using a retinoscope (a special hand-held instrument) while holding different lenses in front of each eye to measure refraction (Repka, 1998). The child does not need to say anything during this part of the examination, although it is helpful if the child remains still (Stiles & Knox, 1996).

The video *Vision Tests for Infants* (Chen & Orel-Bixler, 1997) provides a visual demonstration of the procedures described above. Activity A provides the opportunity to view this video and have participants discuss related questions.

Families may expect the information described below from the eye exam (Stiles & Knox, 1996).

- An explanation of the child's visual condition and prognosis. It is important that the family have a sound understanding of the diagnosis and prognosis, not only for their own benefit but so that they are able to describe their child's diagnosis to others if team members change and the family has to work with other professionals.
- Information about secondary visual conditions. For example, retinopathy of prematurity may be accompanied by strabismus, an eye muscle misalignment. Sometimes glaucoma, an elevated pressure in the eye, can be a secondary condition associated with cataracts. (See Session 3 for more information on specific visual conditions.)
- A prescription for the best corrective lenses, if applicable. The family and TVI should ask about a prescription if the eye care specialist does not automatically give them one for the child. Most children should be tested for prescription lenses; however, not all visual conditions can be corrected with lenses.
- Information about the size of objects and materials the child is able to see and the distance at which the child sees objects or people. For example, the child might be able to fixate and follow a 1-inch finger puppet at a distance of 12 inches. (The TVI and eye care specialist may differ in their observations and recommendations because the child's visual functioning may vary depending on setting—natural environments or clinical settings.)
- Recommendations for best lighting for the child, especially if dim or bright lighting is particularly challenging or optimal for the specific eye condition. (Again, the TVI and eye care specialist may differ in their observations and recommendations because the child's visual functioning may differ in natural environments compared with clinical settings.)
- A prescription for medication, if necessary, to treat ocular conditions or infections (e.g., glaucoma or conjunctivitis)

- Information about physical activities. In some cases, such as conditions involving retinal detachment, the eye care specialist may restrict the child's physical activities to prevent further vision loss and decreased ability to use vision.

Families may find that taking their child to the eye care specialist is a challenging experience. Although families may vary, the reasons could include discomfort with professionals, feeling intimidated because they do not know what to expect, concern because they have difficulty communicating with professionals, different (and conflicting) expectations due to different cultural backgrounds, or occasional adverse reactions from the child. According to Hanson (1998), families of children with disabilities are required to make adaptations that are not required of a family with a child without a disability. Further, families may be culturally disinclined to make visits to medical professionals (including eye care specialists) and accept the accompanying "intrusions" of interventions and home visits.

C. Supporting families following the diagnosis of visual impairment

Many families report that receiving a diagnosis of a visual impairment for their child can be a difficult experience (Leyser, Heinze, & Kapperman, 1996); therefore, TVIs should refrain from judgmental statements or giving unsolicited advice. They should, however, practice reflective listening.

Reflective listening is when professionals quietly and calmly listen to families without trying to make them feel better or solve their problems. When discussing issues with families, TVIs should be aware of the types of responses they can offer families, and how those responses may be received. Responses of professionals can be separated into four categories that are described below.

- *Critical response.* The receiver has made a judgment about the content of the sender's message. These responses can have a detrimental effect on developing trust with another person. For example, if a parent expresses doubt or weariness, the TVI might respond, "You shouldn't take a defeatist attitude." The parent might take the TVI's comment to be critical and alienating.
- *Clarifying response.* The receiver probes by asking further questions. Open-ended questions encourage people to answer in greater length and detail. For example, the TVI might ask parents to explain what the eye care specialist told them during the child's last eye exam.
- *Empathy response.* The receiver gives an understanding and reflective response in order to better comprehend the sender's thoughts and feelings. Be careful to demonstrate care rather than "taking care of" the family or adopting their problem.

An example of an empathetic response might be, “Hearing that Susie’s vision is getting worse must have been difficult for you.”

- *Recommending response.* In response to a parent’s description of a problem, the interventionist attempts to teach or tell the parent how to solve the problem, or impart some wisdom to the parent. A recommending response might make the parent defensive and could discourage open sharing of thoughts and feelings. For example, the TVI might inadvertently offend a parent by saying, “A consistent approach will encourage Johnnie to wear his glasses.”

TVIs should assist families during the potentially difficult period of understanding and accepting the diagnosis by being emotionally supportive (demonstrating a positive attitude, responsiveness, orientation to the whole family, friendliness, sensitivity, and competence) and by offering emotional and informational support (Hatton, McWilliam, & Winton, 2003). Families may need time to accept and adjust to the diagnosis. Nevertheless, TVIs can be especially helpful by being alert for opportunities to selectively share encouraging stories with families about other families’ successes. Gently sharing these stories (always with sensitivity to issues of confidentiality) may help families feel optimistic about the future. Session 3 of the *Family-Centered Practices* module presents additional information about providing support (Hatton et al., 2003).

As noted in the *Family-Centered Practices* module, Leyser and Heinze (2001) found that families often report a need for more information when learning about their children’s diagnoses. Many resources for addressing this need are available via the Internet. Additionally, TVIs might develop their own handouts (at least on the most common visual conditions), being sure to explain the medical basis for the condition as well as the visual implications. TVIs must fully understand the structure and function of the eye so that they can explain the child’s visual condition and its implications within that context. See Activity C for suggestions about researching visual conditions and locating resources to share with families.

Types of support

TVIs provide families and other team members with informational, material, and emotional support. Session 3 of the *Family-Centered Practices* module provides information on these forms of support.

Emotional support specific to the child’s visual condition and visual functioning might involve

- introducing the family to another family who has a child with the same visual condition or a child who functions similarly visually. The families can share their experiences with each other and provide support to one another.
- listening empathetically to families as they share their concerns, frustrations, and victories related to their child’s visual condition and visual functioning.

- introducing families to adult role models with the same visual condition as the child. The adult can talk about the successes, challenges, and other experiences he or she has had in achieving the current level of independence.

Informational support specifically related to the child's visual condition and visual functioning may include

- videos, written information, models and drawings of the eye, etc., related to the child's specific visual condition and environmental considerations. Handout C provides sources of information to share with families that may assist them in understanding their child's visual condition.
- contact information for eye care specialists in the community, state, or region.
- contact information for support groups and newsletters specific to the child's visual condition.

Material support specific to the child's visual condition and visual functioning may include

- nonoptical devices such as lighting sources (e.g., full-spectrum lamps and Xenon lights) for the family to use within the home and community, sun lenses or indoor nonglare lenses (e.g., NoIR), high-contrast materials (e.g., trays that provide good contrast), and reading stands.
- optical devices, such as dome magnifiers and computer- and television-screen magnifiers, that have been prescribed by low-vision specialist.
- ensuring the child's glasses fit well.

Learning styles

To be most effective in sharing information that may help explain a diagnosis, TVIs should recognize that individuals have different learning styles. These different styles are influenced by childhood development, work experiences, and cultural background. Individuals who prefer to be introduced to an overview or the "big picture" followed by individual, specific facts comprise 55% of the general population and are called global processors (McCarthy, 1987). Analytical processors, on the other hand, are those individuals who prefer receiving the individual facts first in order to understand the bigger picture (estimated at 28% of the population). Approximately 17% of the population is comfortable processing information either way. TVIs and all team members can benefit from knowing a caregiver's preference for acquiring new information. If information is presented to caregivers in an efficient and effective manner, communication and intervention for the child and families should be enhanced.

In addition to accessing information either globally or analytically, people perceive and then process information in different ways. McCarthy (1987) notes that people perceive information either concretely or abstractly. Both types of perception are equally important. Once perceived, some people process information by being more actively

involved with it, while others reflect more about what they are learning. The combination of the two dimensions of perceiving (concrete and abstract) and two dimensions of processing (active and reflective) results in four different learning styles. (For additional information about learning styles refer to Bernice McCarthy's book entitled *About Teaching: 4MAT in the Classroom* (2000) and Verster's *Learning Styles and Teaching* (n.d.), available from http://www.teachingenglish.org.uk/think/methodology/learning_style.shtml.)

When Ceci, the TVI, went to the Thomas home she was happy to see that both parents were there for her initial visit to see their 3-month-old son, Zach, who has aniridia. Over the years, Ceci has found that it is important to talk with her families to find out how they best learn and how they prefer to receive information. She began her visit by asking Mr. and Mrs. Thomas what they knew about Zach's visual impairment and if they had any questions.

Mr. Thomas immediately explained the intricacies of aniridia to her, noting that his brother is a medical student, and they had spent time together researching the condition on the Internet and in medical textbooks. He said that it was important for him to have all the facts and asked Ceci several questions about his son's future, such as whether he would walk at 12 months and whether he would be able to go to college. At the same time, Ceci noticed that Mrs. Thomas appeared anxious and overwhelmed by all the information being exchanged. When Ceci asked her if she had questions, Mrs. Thomas said that she was so overwhelmed with information that she did not know what to ask.

Ceci made a mental note about differences in the amount of information these two parents wanted. The father seemed to be a global processor who wanted all the facts and to understand the big picture. On the other hand, the mother appeared to be an analytical processor who might be overwhelmed with too much information. Therefore, providing information to the mother upon request might be best for her. Ceci would keep this in mind during future home visits as she shared information with either or both of the parents.

Families of children with visual impairments may find that contact with another family whose child has a similar visual condition or contact with successful adults with visual impairments may be helpful in providing role models and optimism for the future. TVIs should be cautious in making introductions to families, especially those with a new diagnosis. When selecting individuals to introduce to the family, care must be taken to ensure that the "model" family or adult is a positive example who will interact with sensitivity and optimism. The TVI might consider families who appear to have successfully adapted to their own children's diagnoses, who are involved with early intervention, and who can articulate their experiences in a helpful way. Sometimes TVIs can link families with similar values, culture, and educational levels. In all cases, TVIs must maintain high levels of confidentiality and only suggest contacts for families who

would welcome them. Likewise, adults who might be introduced to a family should have a similar visual condition; have experienced some success educationally, professionally, or in the community, possibly even being a leader in the community or field of visual impairment; and generally be positive about the future for children with visual impairments. Families may be interested in hearing about challenges as well as success that these adults with visual impairments have experienced in reaching their current level of independence. National and regional support groups may also offer resources and a network of contacts that would be helpful to families.

Vision simulators

Another strategy TVIs might use to help families understand diagnoses is to help simulate various visual conditions. When family members have normal vision, it may be difficult for them to understand how their child's visual abilities differ from their own. TVIs can assist families in understanding a specific visual condition by using vision simulators. Vision simulators are available commercially or can be made by hand. (See Handout D for a list of sources to obtain commercial vision simulators and Handout E for a description of how to make homemade vision simulators.) Families or professionals should not be coerced into using simulators and should remove them if they become nauseated or disoriented.

When using vision simulators with families or other professionals, it is important to remind users of limitations to their use.

- The vision simulators are only an approximation of what the child sees.
- Unlike typically sighted individuals, who know what things look like, children with visual impairments may never have seen things in a typical way. Thus, these children may not recall from memory what something looks like.
- Children may have secondary visual conditions in addition to their primary diagnosis. If the child also has astigmatism, strabismus, or glaucoma, simulating cataracts alone will not provide an accurate description of the child's visual function. The combination of two or more conditions will affect the child's use of vision and understanding of what is seen.

When TVIs use vision simulators with families, they should consider the type of activities the family members may complete while wearing the simulators. Individuals should be seated while wearing the vision simulators for safety. If the family members want to experience movement (if the child is having difficulty going downstairs, for example), the vision simulation experience should begin with a seated activity and then progress to a movement activity. Families should not be pressured to use the simulators. Perhaps the simulators can be left with the family so that they can try them at a convenient and private time and so that all of the members of the family have the opportunity to try them.

TVIs should consider planning simulation activities that replicate the challenges and difficulties the child might be experiencing.

Nico's mother finds that when she feeds her son in his highchair, she ends up spending 15 minutes cleaning the kitchen afterwards. Nico makes quite a mess with his spoon, often spilling food over the side of the bowl or flinging it off of his spoon rather than getting it in his mouth.

To help her understand what Nico is experiencing, Nico's mother is given vision simulators corresponding to what her son with glaucoma may see. She sits at the kitchen table with a white placemat in front of her that contains a white bowl of vanilla pudding. The bowl is very shallow, and so the pudding fills the bowl. She is asked to eat the pudding with her nondominant hand. (Her nondominant hand is a more realistic simulation of what Nico's motor skills may be like as a 16-month-old.) After she is finished and removes the vision simulators, she sees that she, too, has made a mess. Having taken the time to simulate Nico's visual impairment and to complete an activity she expects him to do, Nico's mother may better understand the challenges her son is currently experiencing.

Following the activity, she and the TVI can explore ways to make the activity easier for Nico—for example, by using high contrast materials and a deeper bowl and by placing the bowl on a sheet of Dycem (nonslip plastic).

D. Language barriers and cultural issues

Language barriers

When English is not the family's primary language, it will be important to have an interpreter (when using oral communication) or translator (for use with written information) present when meeting with eye care specialists. Families may find the diagnosis of a visual impairment and its implications difficult under the best of circumstances, so a language barrier could complicate an already challenging situation. A skilled interpreter or translator can help them meet these challenges by providing accurate interpretation of information from the eye care specialist and TVI. Younger or extended family members should not be pressed into service to interpret complex medical information. Interpreters should receive advance preparation about what will occur in the exam so they can accurately interpret information and promote communication between the family and eye care specialist (Chen, Chan, & Brekken, 1999). For more information about working with translators and interpreters, please refer to *Conversations for Three: Communicating Through Interpreters* (Chen, Chan, & Brekken, 1999).

Milian and Conroy (2001) provide guidelines for professionals who provide services to English-as-a-second-language students with visual impairments who use interpreters and translators. To address the needs of caregivers of very young children with visual impairments, the following guidelines have been adapted from Milian and Conroy (2001).

- Avoid asking nonprofessional bilingual persons to fulfill the role of interpreter/translator when they have not received appropriate training. For example, although the eye care specialist's secretary speaks Spanish, she should not be asked to interpret for a Hispanic family.
- Use qualified bilingual professional personnel before seeking the assistance of interpreters or translators. In other words, a Spanish speaking TVI or teacher might be a better choice than someone who speaks Spanish as a primary or secondary language.
- Explain the importance of confidentiality when asking interpreters or translators to interpret dialog during meetings or to translate confidential documents.
- Explain the importance of neutrality and impartiality in interpreting or translating to the person who will be involved. Omissions, alterations, additions, making personal statements, or offering opinions should be avoided.
- The TVI should monitor the interpreters and translators to ensure that they are not working in isolation.

Cultural issues

For detailed insight into specific religious and ethnic interpretations of visual impairment, we recommend *Diversity and Visual Impairment: The Influence of Race, Gender, Religion, and Ethnicity on the Individual* (Milian & Erin, 2001). TVIs should realize that we cannot assume that all families, even with very similar cultural backgrounds, will be influenced equally or in the same manner by cultural traditions, values, and histories. Each family must be addressed as a unique entity with its own strengths and challenges.

Professionals in the field of visual impairment may have encountered the following responses regarding visual impairment among different families (Erin, 2002). This list demonstrates a wide range of responses in terms of cultural values and norms. Professionals must approach all situations without judgment knowing that they will be ineffective in supporting families and children with visual impairments if they try to impose their own biases and beliefs.

- Families from some cultural groups believe that the family should care for and support the child with a disability, and they do not see independence as an important value. This is especially true of travel: many families do not expect or want their child to travel independently and believe the child's role is to receive assistance from others. Professionals often are concerned about whether to encourage

independence for a child who is blind if the family does not expect the child to function without assistance.

- Some families also come from cultures where individuals with blindness or severe visual impairments are not expected to hold jobs, or are expected to hold only certain jobs. For example, until recently, in many Asian cultures, individuals with blindness were prepared mainly for careers in massage or fortune telling.
- While the majority culture in the United States tends to trust written communication as the clearest and most consistent method of planning (e.g., IEP meeting), people from some cultures tend to value oral communication. Information conveyed only by letter is not trustworthy for some families. Direct contact from school personnel is more important to them.
- Gender expectations, socialization, and roles in the family vary across cultures. It is important to discover what toys are typically used by children of the same age and gender as the child with a visual impairment and to incorporate these into learning activities so that the child is more likely to interact with peers.
- Some cultures view specific types of visual impairments as having special meaning within the culture. For example, people with albinism may be considered as having special powers in some cultures, while in others they are believed to bring bad luck. Professionals might ask parents how others in their community react to their child in order to find out about these perceptions.
- Many religious and cultural groups still connect the presence of visual impairment with the idea of retribution for sin. This tends to be more common among grandparents' generations, but professionals may be concerned about how to react when a family expresses a belief like this. For example, professionals may struggle with the appropriate response: should they disagree; should they support the family's belief even though they feel that it is not founded in fact; or should they talk to the family about how this might affect the child?
- People in leadership roles vary within families. For some families, religious leaders and heads of families may be the critical decision-makers. Providing effective early intervention may involve including these leaders or at least gaining their approval for the family's participation in an intervention program.
- It may be common for families from some cultures to visit religious healers during their children's early years. Many families do not necessarily expect healing but rather support from their religious community. Professionals should be aware that this does not necessarily reflect a belief that there will be a physical change in the child's condition, but rather a family's effort to understand and accept the meaning of the disability.

In other situations, cultural backgrounds and interpretations may prevent families from accepting the diagnosis. Some cultures may not view visual impairment the way that many middle-class Americans do and may not be motivated to treat the visual impairment or provide interventions. Others may understand the visual condition but

have a different interpretation of the cause, such as a punishment for sin. (Session 1 of the *Family-Centered Practices* module presents information on the implications of various cultural backgrounds on issues of visual impairment.)

Jesse and his mother Nellie Tsosie are Navajo Native Americans and visit the eye clinic on their reservation to monitor Jesse's glaucoma. Medical professionals at the clinic recommend medication to treat the glaucoma. Nellie Tsosie discusses Jesse's eye condition with the medicine man of her tribe, who determines the cause of the disease to be lightning in the sky. He recommends and organizes a community sing to eliminate the glaucoma. Jesse's family strongly believes the community sing may have an impact on Jesse's vision.

It is important for TVIs to practice cultural reciprocity. Cultural reciprocity refers to a two-way process by which service providers and families from different cultures find mutual ground through sharing information about values and culture that forms a basis for effective communication. Cultural reciprocity does not require TVIs to give up or change their values, but it does require openness, a willingness to learn and understand, and an ability to regard families in a positive light. According to Harry (as cited by Warger, 2001), professionals may consider following a four-step process that will help them develop cultural reciprocity. The four steps to this process are described below.

- Step 1. Identify your own cultural values as you interpret a child or family's difficulties or as you recommend services.
- Step 2. Determine whether the family is aware of and values your assumptions—if not, how do your views differ.
- Step 3. Identify and respect cultural differences between you and the family—explain the cultural basis of your assumptions.
- Step 4. Determine the best way to adjust your recommendations to match the family's values through collaboration and open dialogue.

In Jesse and Nellie's case, the TVI may feel compelled to share her values about medical treatment for glaucoma. In addition to supporting families, TVIs have obligations to the children that they serve and must advocate for the child if the child's welfare or health is concerned. Jesse's TVI, Margaret, might engage in the following exchange with Nellie about their different values regarding medical treatment for Jesse.

First, Margaret realizes that she values high-quality, scientifically based medical care and that she is troubled at the prospect of the Navajo medicine man coordinating Jesse's medical care.

Next, as the second step, Margaret asks Nellie, "Can you tell that I'm a little anxious when you tell me about taking Jesse to the medicine man for his glaucoma?" When Nellie acts surprised and says, "Well, I knew you acted uncomfortable, but I thought you

were just having a bad day,” then Margaret can share information about her own values regarding medical care as the third step in the cultural reciprocity process.

Margaret might say, “I recognize that meeting with the medicine man about Jesse’s medical care is important to you. However, I’m concerned about Jesse’s vision and would like to share my values so that we are both aware of our different views about Jesse’s medical care. High-quality medical services that are based on the latest scientific findings are very important to me. My father and grandfather are both doctors, which probably explains why I’m very tuned in to prevention and the importance of current recommended practice. I know that you value the medicine man and his input, but I am concerned that Jesse might lose his vision if you rely solely on him.”

Finally in Step 4, Margaret resumes, “I value the relationship that we have developed to support Jesse, and I would like for us to find a way to work through this situation. Because glaucoma can lead to blindness, I’m very concerned about Jesse receiving high-quality medical care from a pediatric ophthalmologist.” Nellie might respond, “Margaret, thank you for sharing your values about Jesse’s medical care. I’m relieved to know what was making you anxious. Although we will see the medicine man, we will not abandon Jesse’s regular medical care with his pediatric ophthalmologist.”

E. Helping families prepare for and communicate with eye care specialists

In general, TVIs begin working with a family after the child’s initial eye exam. (Most early intervention programs require an eye report before the child can be enrolled.) In this situation, TVIs can determine what the family understands about their visit to the eye care specialist by following the steps described below.

- Ask the family what they were told.
- If appropriate, take notes while letting the family talk, so you can refer back to them at a later time.
- Ask the family if they have any questions.
- At the end of the discussion, choose a relevant concern from the topics discussed to share additional information with them, if they would like this information.
- Find out when the next visit to the eye care specialist will occur.

It is the TVI’s responsibility to help families understand diagnoses by interpreting and explaining diagnoses as indicated on the eye report and to support families as they process the information. (Refer to Handout F for more information on interpreting eye report abbreviations and refractive errors.)

In anticipation of subsequent visits to eye care specialists, or if the initial visit has not occurred, TVIs can assist families in preparing for the exam. First, TVIs can review the

components of most eye exams (as outlined in Major Point A) to familiarize families with the steps of the exam and their purpose. Next, TVIs can help caregivers formulate questions they would like to ask about their child's visual etiology, prognosis, and current treatment options (e.g., prescription lenses, surgeries, and medications). Most doctors are pressed for time. Families who have well-developed lists of questions to ask during the exam can learn more about their child's condition in an efficient manner.

Handout G provides a list of questions caregivers might want to ask the eye care specialist. Families may use these questions as a starting point for developing their own list. Some families will prefer to write their questions down so they will not forget them. Others may prefer to have a few questions in mind to ask. TVIs can assist families in planning how to bring and ask their questions during the eye care specialist's exam.

TVIs can also help caregivers in anticipating what eye care specialists might ask them. To be prepared for these questions, the TVI can help caregivers organize observations of their child's visual abilities by interviewing them and recording their verbal accounts of how their child uses vision. Handout H can be used to assist TVIs in recording their observations of children's visual function within routine activities. For example, with Kermit (Handout H) the TVI observed the child during bath time. She recorded the steps in the activity and noted the factors that affected vision. Kermit's visual behaviors were recorded and can be compared with vision use in other routines to note consistencies and discrepancies of visual behavior. The TVI and Kermit's caregivers can discuss what was observed using the recorded notes (Handout H) as a basis for their discussion. The caregiver can also share these notes with the eye care specialist. Discussing the results of the functional vision assessment with the family will also help caregivers understand their child's visual functioning. (Functional vision assessment is covered in Session 4 of this module.)

The family may ultimately decide to develop a portfolio (Handout I) of the child's medical and educational information that can be taken to the eye care specialist and other medical exams and can be shared with other team members and professionals. When the child has multiple conditions and sees several professionals, a portfolio may be particularly helpful and efficient for organizing, maintaining, and accessing reports, notes, referrals, and other information. Portfolios may be useful for children with special needs.

Stiles and Knox (1996) provide strategies that may help make visits to the eye care specialist less stressful and more pleasant.

- Complete medical forms (and insurance forms, if applicable) before the appointment, if possible. Eye care specialists' offices may provide the forms ahead of time to reduce time spent in the office. Before the appointment, inquire about questions the eye care specialist might ask so that parents or caregivers can be prepared.

- Caregivers should try to avoid conveying negative feelings or emotions about the eye exam to the child. Children are perceptive about their caregivers' feelings. Even conversation not directed at the child may influence the child's attitude about the eye care specialist and examination. Talking matter-of-factly or in a positive manner about the eye exam may help the child have a positive attitude.
- Have some of the child's favorite possessions (toys, books, or tapes) available to play with in the waiting room in order to keep the child entertained and in a good mood. The eye care specialist might have toys and books in the waiting room that are new and engaging, but the child may feel more comfortable playing with familiar toys. Easy-to-manage snacks might also be considered.
- Make the trip to the eye care specialist's office something to look forward to (or at least not dreaded) by planning a treat after the appointment. A trip to a favorite park, restaurant for a snack, or visit to a special friend would reward the child for having the exam.
- Try to schedule the appointment for a time of day when the child is most likely to be alert and cooperative.

TVIs can offer to accompany the family to the appointment. Some families will appreciate having someone who knows their child and his or her visual abilities to accompany them. In this role TVIs are a support to families and do not monopolize eye care specialists' attention or dominate visits. TVIs encourage families to interact with eye care specialists in order to build relationships. Educational professionals will come and go in the life of the child and the family, so assisting families in establishing their own relationships with medical professionals is crucial. TVIs can interject at an appropriate time, especially if communication between the eye care specialist and family is not progressing well. They may also ask additional questions to guide the eye care specialist in clarifying explanations (e.g., how the child's specific visual condition impacts his/her ability to use vision), or may encourage the family to share additional information (e.g., how the baby often stares at a black and white bear when lying in her crib on her left side).

If the TVI is unable to attend the appointment with the family, the caregiver and TVI can prearrange a follow-up call to talk after the appointment. The call can serve as a way for the caregiver to discuss any information or concerns following the appointment.

F. TVI as liaison

TVIs can assume the responsibility for initiating interactions with eye care specialists through letters of introduction, phone calls, or electronic mail. However, before TVIs can collaborate with specialists, they must secure written permission from families in order to exchange information. Sample forms for releasing and exchanging information can

be found as Handout J. Although most eye care specialists will value TVIs' educational expertise, they may not have time to initiate interactions with TVIs. Some eye care specialists are not knowledgeable about the benefits of early intervention, and they may not be aware of services for families of young children with visual impairments, including those with multiple disabilities. Thus, TVIs have a unique opportunity and responsibility to establish collaborative relationships with eye care specialists.

In the context of these collaborative relationships, TVIs and eye care specialists will learn more about each other's roles and about services that are available on a local, state, and national level. TVIs can also provide the eye care specialist with information about appropriate referrals for early intervention services. Eye care specialists may see families prior to their entry into the early intervention system and consequently may be the initial referral source, making this information especially important.

Although most eye care specialists are usually very busy examining patients or performing surgeries, some are relieved to have more information about a child's visual functioning in daily routines and activity settings prior to the clinical eye exam.

- TVIs and families can provide information about visual functioning in day-to-day activities to provide insight that will supplement observations made in a clinical setting.
- When writing letters of introduction to eye care specialists, TVIs should provide an overview of how the child uses vision during daily activities in a variety of natural environments, as well as include information from the functional vision assessment report.

TVIs who have established relationships with eye care specialists may be in a better position to ask questions and share information with other members of the team, thus serving as a liaison. Professionals in other disciplines, in turn, may also need to seek the assistance of TVIs to further understand the impact of specific visual impairments on children's development and learning.

Two-year-old Taylor, who has cerebral palsy and cortical visual impairment (CVI), responds most consistently to familiar red or yellow objects that are presented on his right side in his upper field. Knowing that Taylor appears to see objects in a particular visual field better, Taylor's grandmother is concerned about the switch the speech language pathologist (SLP) has introduced to Taylor. The SLP is using a blue switch and placing it directly in front of Taylor on the tray of his wheelchair. Taylor's responses to the switch are inconsistent, yet his grandmother feels he is capable of understanding how to use a switch. When she asks the TVI for her opinion, the TVI suggests that she and the SLP visit the home together so that they can share information with each other.

Once the TVI provides the SLP with additional information about CVI and information she has gathered through the functional vision assessment (FVA), the therapist realizes she is not using an appropriate switch for Taylor, nor is she positioning it to promote his independence. After she makes modifications to the switch by covering it with yellow plastic and placing the switch on a slant board in his upper right visual field, Taylor activates the switch more frequently and consistently.

The collaboration modeled among team members in the vignette above is characteristic of the transdisciplinary model of service delivery. According to Smith (1998), the transdisciplinary model is exemplified by the sharing of information among specialists, instructors, and family members and role release that permits the primary service provider to integrate recommendations from different disciplines. Correa, Fazzi, and Pogrud (2002) suggest that three elements are necessary for a transdisciplinary team to work successfully:

- collaboration (working together as a team),
- an attitude of staff development (cross-training or sharing of expertise, skills, and knowledge among team members), and
- role release (the subsequent release of discipline-specific responsibilities across disciplinary boundaries once another team member is cross-trained in a specific skill or knowledge area).

The purpose of role release within the transdisciplinary model of teaming is to provide high quality intervention services to the caregiver and child. It does not mean a team member will give up responsibility for providing a service to the team. Nor does it mean that the role of any team member may change depending on the type and frequency of needs of the child and family. In practice, team members will shift roles depending on the knowledge and skill of other team members. Building team relationships means that all members should engage in continuous collaboration as they monitor and refine intervention goals for the child and family (Topor, Holbrook, & Koenig, 2000).

Correa et al. (2002) describe the benefits of the transdisciplinary approach as follows.

Skills taught in short episodes twice a week may not be easily integrated into the child's repertoire. For example, if O & M skills are only practiced when the O & M specialist comes to the preschool, the child who is visually impaired will most likely not incorporate the skills into his or her everyday activities in a meaningful way. If the classroom teacher and assistant are shown the appropriate skills and have the child utilize them, then the daily reinforcement will help the child functionally interpret the skills. (p. 421)

The transdisciplinary team model is more difficult to sustain than other team models because it requires coordination, collaboration, and role release and consequently may take more time to implement. Team members in this model must learn from each other

in order to cross disciplinary boundaries. Therefore, time must be available for team members to train each other. Professionals find that one of the biggest challenges with this model is finding time to meet (Correa et al., 2002). Scheduling ongoing meetings with team members is essential. Alternative methods of communication (including email, phone calls, faxes, and written communication) and videotaping all contribute to the increased communication that this model requires. (Session 2 of the *Family-Centered Practices* module addresses effective teams.)

Finally, the TVI will serve as a liaison between eye care specialists, other team members, and families. Families' experiences with eye care specialists will vary considerably. Some families will report having positive experiences with eye care specialists, while others will report negative experiences. Families may experience negative emotions such as frustration, anger, depression, concern, and intimidation as a result of an unsatisfactory clinical eye exam. Families may experience negative emotions because family members were unable to understand the diagnosis, were devastated by the diagnosis, felt rushed during the visit, did not understand the procedures used during the exam, were frustrated because the eye care specialist was unable to provide a definitive diagnosis or prognosis or was not sensitive to the child or family (Killebrew & Corn, 2002). In addition, families may have received information that contradicts their own observations or information from other professionals.

An eye care specialist indicates that Quinn does not appear to have any useful vision, yet Quinn's father observed him turning toward the light that comes in from the kitchen window, smiling at the mobile above his crib, and reaching out to grab for the family cat as she runs past. On one hand, the doctor is telling the father that his son is blind, and yet on the other hand, the father is sure his child can see some things in his environment.

In situations like that described in the vignette above, the TVI can follow up with the eye care specialist to gather more information. The eye care specialist may have been referring to the child as being legally blind, a term that families may have a difficult time fully understanding. Or perhaps, because the baby did not respond to the doctor's visual stimuli in the office, the doctor erroneously assumed the child was blind. Environmental factors may have been a variable in the child's lack of visual responses. In a familiar environment such as his crib or the living room with favorite toys and people, the baby may use his vision more efficiently than in an unfamiliar environment such as the examining room.

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