

Appendices to accompany *Early Intervention Guidelines for Infants and Toddlers with Visual Impairment in Washington State* (January 2008 version).

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Appendix A

**Position Paper: Division of Visual Impairments,
Council for Exceptional Children**

October 19, 2003

**Family-Centered Practices for
Infants and Young Children with Visual Impairments**

Position Statement, Division on Visual Impairments, Council for Exceptional Children¹

October 19, 2003

Family-Centered Practices for Infants and Young Children with Visual Impairments

Introduction

Legislation and research affirm the importance of early intervention for young children with disabilities as well as early intervention that is family centered. Family-centered practices are based on collaborations between families and professionals that not only facilitate the optimal development of the child but also address the concerns and priorities of families. Family-centered practices are characterized by:

- focusing on the strengths of families while respecting and honoring diversity.
- empowering families to make their own decisions about resources and services.
- viewing the family holistically.
- collaborating with families and other members of the early intervention team.

This position paper outlines basic principles that should be addressed in the implementation of early intervention and preschool services for infants and young children with visual impairments (birth to six years). Although children with visual impairments represent a small group within the population of children with disabilities, they have diverse and unique needs that result from challenges in accessing the visual environment. To meet the legal mandate for appropriate support for infants and young children with visual impairments and their families, this paper will describe issues and supports that must be addressed in order to provide basic services.

Developmental Needs

The impact of visual impairment on development begins at birth. The mutual eye gaze observed between infants and their parents facilitates attachment between them. Indeed, some psychologists (Schore, 1994) have theorized that this eye gaze actually stimulates brain development in infants. Very young infants and their caregivers typically spend considerable time gazing and smiling at each other and also imitating each other. Later, eye gaze is used to establish joint reference to objects of interest. When vision is impaired, attachment and communication between parents and infant present a challenge. Because strong attachment between infant and parents is related to developmental outcome, early intervention that is focused on strengthening attachment between infants with visual impairment and their caregivers and family is

¹ This position paper and others relating to vision impairment can be found on the following website: www.cccdvi.org/positionpapers.html

recommended. Typically, very early intervention for infants with visual impairments and their families is directed to helping caregivers interpret communicative cues of their infants while also helping them use appropriate communication cues that may not be as dependent on intact vision.

Infants and young children with visual impairments have the same needs as all children, as well as some unique developmental needs. Vision is the primary organizing and integrative sense for the sighted child; the remaining senses, particularly the tactile and auditory, become more important for the child with a visual impairment. Unless specific intervention, particularly in maximizing efficient use of all senses and in symbolic operations and concept development, is introduced, many young children with visual impairments will not be able to form accurate concepts of the world around them. Children with visual impairments require specific interventions designed to promote optimal use of vision and all senses, including the use of environmental adaptations and optical devices. In order to assure that young children with visual impairments use all sensory input as effectively as possible to maximize learning and facilitate development, professionals must collaborate with families to facilitate their understanding of their children's unique strengths and challenges.

Many infants and young children with visual impairments have different perceptions of the world than children with normal vision. Concepts are built on perceptions of the objects and events in the world that result from information processed by our senses. Consequently, an understanding of the world that results from information obtained primarily through tactile, auditory, olfactory, and kinesthetic information, rather than vision, must be different. Vision is particularly important for information about objects, people, and events at a distance. Although hearing does provide some information about distance, it typically does not provide the stable and consistent information provided by vision. Thus, development in all areas, including cognitive, social-emotional, communicative, and motor development, as well as the development of daily living skills, may be quite different for children with visual impairments. These differences in development, combined with lack of access to the visual environment, must be considered and addressed through early intervention that:

- addresses family concerns and priorities.
- assesses and maximizes the unique sensory capabilities and preferences of each child.
- adapts environments to make them accessible and to maximize effective use of all senses.
- provides appropriate experiential learning opportunities that facilitate development in all domains.
- facilitates acquisition of emergent literacy skills for potential braille and print readers.
- facilitates engagement, independence, and the development of social relationships.

Children with multiple disabilities often have needs that are even more distinctive than those of children with visual impairment as a single disability. When visual impairment is compounded by other disabilities, professionals with expertise in other areas, such as augmentative communication or assistive technology, will be required, as well as those who understand positioning and handling and other special needs such as deafblindness.

Regardless of the extent and types of disabilities, close collaboration among all specialists, the family, and qualified professionals with knowledge of the impact of a visual impairment on development and learning is essential.

A visual impairment has an immediate and lasting impact on the child and the family. Parents, siblings, and extended family members may experience considerable stress at the time of diagnosis and throughout their lives unless they receive the specialized supports required to meet their unique needs. As mandated, the strengths, needs, and concerns of families must be addressed in developing and implementing the individualized family service plan (IFSP). A family-centered approach can facilitate the identification of family concerns and priorities and effective strategies for responding to those concerns and priorities on an individual basis for each child and family. From the time the visual impairment is identified, the family and child should have ongoing, individualized support and services. Initially, the primary focus should be on the establishment of attachment between parent and child. Through continuous close collaboration, professionals and families can facilitate the child's optimal development while also addressing the concerns and priorities of families.

Recommended Practices

When vision is impaired, it is more difficult for children to acquire efficient, holistic, and simultaneous information about people, objects, and the environment. This inability to obtain detailed information through a single glance affects all areas of development—even the most basic concepts can be altered. Children with visual impairments have access to efficient learning about the world only when primary caregivers, family members, and professionals consciously and consistently provide experiences that make maximum use of all senses. For most children with visual impairments, systematic learning does not occur incidentally or spontaneously.

Intervention and educational services may be provided in a variety of settings—the home, childcare centers, community-based preschools, specialized class placements, residential schools for the blind, or in any combination of these settings. Although the Individuals With Disabilities Education Act (IDEA) of 1997, Part C, specifies that early intervention be provided in natural environments with nondisabled peers, that same document also calls for support that addresses family concerns and priorities as well as needs identified during a multidisciplinary assessment. Family strengths and priorities as well as the results of the multidisciplinary assessment are used as a basis for developing outcomes for the IFSP and identifying the settings in which early intervention

takes place. IDEA guidelines specify that the rationale for providing supports and services in settings other than those with nondisabled peers must be described in the IFSP, suggesting that there are instances in which the early intervention team may determine that specialized settings may be appropriate. Because of the unique needs of children with visual impairments and their families, it is important that an array of service and support options be provided. Practices should include:

- recognition of and respect for the family as the most influential factor in the child's growth and development.
- immediate comprehensive support for families that includes information, assurance, hope, and confidence, and that facilitates the development of strong relationships between the child and family.
- comprehensive supports and services, based upon the collaborative development of an individualized family service plan (IFSP) for infants and toddlers and an individualized education plan (IEP) for preschoolers, that consider families' culture, values, strengths, concerns, and priorities.
- supports and services that are individually designed to meet the global and specific needs of each child and family.
- facilitation of cognitive, social-emotional, communicative, sensory, and motor development, as well as the development of daily living skills and orientation and mobility skills, through appropriate experiential learning within daily routines in order to promote engagement, independence, and the development of social relationships.
- assessment of the unique sensory capabilities and preferences of the child in order to identify appropriate environmental adaptations and intervention strategies, including the use of low-vision devices that promote accessibility and effective use of all senses.
- facilitation of emergent literacy skills based on the child's sensory preferences and individual learning style, including emergent literacy for potential braille and print readers.
- provision of services by specialists who are appropriately trained to enhance the development and early learning of infants and young children with visual impairments, including assessment, intervention and education planning, and the development or modification of developmentally and functionally appropriate support and services.
- coordination with the medical community as partners in the provision of comprehensive services for children with visual impairments and their families.
- provision of ongoing in-service and professional development for all staff as well as families.

These recommended practices apply to supports and services for all infants and young children with visual impairments and their families, including those with additional disabilities.

Competencies and Functions of Personnel

Understanding the impact of vision loss on development and the subsequent impact of a child with visual impairment on the family is a complex and ongoing process that demands a variety of special skills and knowledge. In addition to the specialized professional competencies of teachers of infants and young children with visual impairments, deaf-blind specialists, and certified orientation and mobility specialists, the numerous service providers, such as family counselors, speech and language pathologists, social workers, physical therapists, occupational therapists, medical and health-care workers, and others, require additional competencies and collaborative skills to provide effective and efficient services.

Service Providers

All service providers for the child and family should have knowledge of typical and atypical infant and early childhood development including visual development. In addition, they should receive ongoing professional training that includes:

- ability to screen for and identify risk factors or behavioral indicators of potential visual impairments.
- childhood development and behavior and on the child, family, and social environment.
- knowledge and understanding of the impact of visual impairments in combination with additional exceptionalities.

Support Personnel

Additionally, support personnel should demonstrate the ability to adapt their specialized training to meet the unique needs of infants and young children with visual impairments and their families and be supported in these efforts through collaborative program planning with professionals trained in the area of visual impairments.

Primary Service Provider

The primary service provider should have the following additional competencies:

1. Skill and sensitivity in working collaboratively and in partnership with families and other team members through effective communication and the use of family-centered practices to share information and jointly plan and implement supports and services that will enhance the child's overall development and address the family's priorities.
2. Ability to assess functional vision and use of all senses in order to plan effective strategies for facilitating optimal use of vision and all senses and to adapt environments to make them accessible.
3. Ability to adapt and use a variety of assessment strategies to accurately

identify the child's strengths and current levels of functioning and the family's strengths, concerns, and priorities, particularly as they relate the child's visual impairment.

4. Ability to create, coordinate, implement, and continuously evaluate intervention and education plans in order to meet the strengths and needs of the child and the family, including use of support personnel and community resources.
5. Ability to work effectively as a team member.
6. Ability to make appropriate referrals to other professionals, e.g., low-vision clinicians or certified orientation and mobility specialists.
7. Ability to function as a service coordinator or case manager if designated.
8. Ability to translate appropriate research into practice.
9. Ability to access appropriate resources such as assistive technology in order to provide appropriate intervention for infants and young children with visual impairments and their families while also helping caregivers acquire life-long advocacy skills that will enable them to access appropriate supports throughout the child's life.

Because many infants and young children with visual impairments have additional disabilities, service personnel must have an understanding of the impact of combinations of disabilities on individual children and their development. This knowledge can assist them in providing support to families that will help them understand their children's unique needs. Additional competencies may be required of professional personnel when providing support to children and families from diverse geographic, cultural, and economic communities.

Position

Infants and young children with visual impairments and their families require appropriate early intervention support and services. Childhood blindness or visual impairment has an impact on the entire family system. Support should begin as soon as a vision problem is diagnosed in order to assist the family and help it facilitate the child's optimal development.

Infants and young children with visual impairments and their families have a right to qualified early interventionists, teachers, and specialists. Individuals specifically trained to provide early intervention and educational services to children with visual impairments include: a) teachers of students with visual impairments, b) certified orientation and mobility specialists, and c) deaf-blind specialists.

Infants and young children with visual impairments and their families have a right to appropriate specialized supports and services. The following components should be integrated into intervention and education plans and services to promote optimal development and independence for each child:

1. Development of attachment and meaningful social relationships and communication skills (listening, turn-taking, personal expression, nonverbal communication, emergent literacy) when vision is impaired.
2. Assessment of sensory capabilities and preferences in order to facilitate the effective use of all senses, including the use of low-vision devices if appropriate.
3. Adaptation of environments, toys, and learning materials to make them more accessible.
4. Use of compensatory skills to accommodate for vision loss (e.g., strategies for accomplishing tasks using touch rather than vision, learning to use all senses as effectively as possible).
5. Cognitive development opportunities that are experience based and designed to teach concepts that are acquired primarily through vision (basic concepts, problem-solving skills).
6. Facilitation of emergent literacy including literacy for potential braille and print readers through collaboration with families and other professionals.
7. Gross and fine motor development (as well as the development of physical control and stamina) with special attention to prerequisite skills required for age-appropriate orientation and mobility and braille and print reading and writing if appropriate.
8. Age-appropriate orientation and mobility instruction (self-directed, independent movement in the environment).
9. Instruction in daily living skills typically acquired through incidental visual learning that must be taught using hands-on, step-by-step procedures to young children with visual impairments in order for them to function independently within natural environments (e.g., self-care skills, ability to do household and classroom chores).
10. Comprehensive family support that includes emotional support and access to information and resources that will help families become life-long advocates for their children.
11. Thorough understanding of medical and visual conditions and their implications for early intervention and education.
12. Recreational opportunities that enhance creativity and enjoyment

References

Division on Visual Impairments, Council for Exceptional Children (1990). *Family-focused services for infants and young children with visual impairments*. Position paper. Retrieved January 3, 2008, from <http://www.cecdvi.org/positionpapers.html>

Schore, A. N. (1994). *Affect regulation and the origin of the self: The neurobiology of emotional development*. Hillsdale, NJ : Lawrence Erlbaum Associates, Inc.

The following participants of the 2002 Seminar on Infants and Young Children with Blindness and Visual Impairments in Berea, KY, revised the original position paper on 11/05/02. Drafts of the proposed position paper were published in *DVIQ* in April 2003 and posted on the Early Intervention Listserv from February through September 2003. Additional revisions were made based on input from the field.

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The DVI Board adopted this position paper at its meeting in Louisville, Kentucky on 10/19/03.

Appendix B
American Academy of Ophthalmology
Policy Statement:
Vision Screening for Infants and Young Children (2001)

Downloaded 1/3/08 from:

http://one.aao.org/CE/PracticeGuidelines/ClinicalStatements_Content.aspx?cid=0ad11e02-6a8b-437e-8d01-f45eb18bc0b6

(Or, go to www.aao.org and Search for: Vision Screening for Infants and Young Children)

**American Academy of Ophthalmology
Policy Statement:**

Vision Screening for Infants and Young Children (2001)

Policy

The American Academy of Ophthalmology and the American Association for Pediatric Ophthalmology and Strabismus recommend timely screening for the early detection and treatment of eye and vision problems in America's children. This includes institution of rigorous vision screening during the preschool years. Early detection of treatable eye disease in infancy and childhood can have far reaching implications for vision and, in some cases, for general health.

Background

Good vision is essential for proper physical development and educational progress in growing children. The visual system in the young child is not fully mature. Equal input from both eyes is required for proper development of the visual centers in the brain. If a growing child's eye does not provide a clear focused image to the developing brain, then permanent irreversible loss of vision may result. Early detection provides the best opportunity for effective, inexpensive treatment. The American Association for Pediatric Ophthalmology and Strabismus, the American Academy of Ophthalmology, the American Academy of Pediatrics, the American Academy of Family Physicians and the American Association of Certified Orthoptists recommend early vision screening.

Vision screening programs should provide widespread, effective testing of preschool and early school-age children. Many school systems have regular vision screening programs that are carried out by volunteer professionals, school nurses, and/or properly trained lay persons. Screening can be done quickly, accurately, and with minimum expense by one of these individuals. The screener should not have a vested interest in the screening outcome. As with all screening programs, vision screening should be performed in a fashion that maximizes the rate of problem detection while minimizing unnecessary referrals and cost. Beginning in the preschool years, those conditions which can be detected by vision screening using an acuity chart are: reduced vision in one or both eyes from amblyopia, uncorrected refractive errors or other eye defects and, in most cases, misalignment of the eyes (called strabismus).

- **Amblyopia** is poor vision in an otherwise normal appearing eye, which occurs when the brain does not recognize the sight from that eye. Two common causes are strabismus (misaligned eyes) and a difference in the refractive error (need for glasses) between the two eyes. If untreated, amblyopia can cause irreversible visual loss. The best time for treatment is in the preschool years. Improvement of vision after the child is 8 or 9 years of age is rarely achieved.
- **Strabismus** is misalignment of the eyes in any direction. Amblyopia may develop when the eyes do not align. If early detection of amblyopia secondary to

strabismus is followed by effective treatment, then excellent vision may be restored. The eyes can be aligned in some cases with glasses and in others with surgery. However, restoration of good alignment does not assure elimination of amblyopia.

- **Refractive errors** cause decreased vision, visual discomfort ("eye strain"), and/or amblyopia. The most common form, nearsightedness (poor distance vision) is usually seen in school-age children and is treated effectively, in most cases, with glasses. Farsightedness can cause problems with focusing at near and may be treated with glasses. Astigmatism (imperfect curvature of the front surfaces of the eye) also requires corrective lenses if it produces blurred vision or discomfort. Uncorrected refractive errors can cause amblyopia particularly if they are severe or are different between the two eyes.

In addition to detection of vision problems, effective screening programs should also place emphasis on a mechanism to inform parents of screening failures and attempt to ensure that proper follow-up care is received.

Recommendations

The American Academy of Ophthalmology and the American Association for Pediatric Ophthalmology and Strabismus recommend an ophthalmological examination be performed whenever questions arise about the health of the visual system of a child of any age. They recommend that infants and children be screened for vision problems as follows and any child who does not pass these screening tests have an ophthalmological examination .

1. A pediatrician, family physician, nurse practitioner, or physician assistant should examine a newborn's eyes for general eye health including a red reflex test in the nursery. An ophthalmologist should be asked to examine all high risk infants, i.e., those at risk to develop retinopathy of prematurity (ROP), those with a family history of retinoblastoma, glaucoma, or cataracts in childhood, retinal dystrophy/ degeneration or systemic diseases associated with eye problems, or when any opacity of the ocular media or nystagmus (purposeless rhythmic movement of the eyes) is seen. Infants with neuro-developmental delay should also be examined by an ophthalmologist.
2. All infants by six months to one year of age should be screened for ocular health including a red reflex test by a properly trained health care provider such as an ophthalmologist, pediatrician, family physician, nurse, or physician assistant during routine well-baby follow-up visits.
3. Vision screening should also be performed between 3 and 3 1/2 years of age. Vision and alignment should be assessed by a pediatrician, family practitioner, ophthalmologist, optometrist, orthoptist, or individual trained in vision assessment of preschool children. Emphasis should be placed on checking visual acuity as soon as a child is cooperative enough to complete the examination. Generally,

this occurs between ages 2 1/2 to 3 1/2. It is essential that a formal testing of visual acuity be performed by the age of 5 years.

4. Some evidence currently exists to suggest that photoscreening may be a valuable adjunct to the traditional screening process, particularly in pre-literate children.
5. Further screening examinations should be done at routine school checks or after the appearance of symptoms. Routine comprehensive professional eye examination of the normal asymptomatic child has no proven medical benefit.
6. School aged children who pass standard vision screening tests but who demonstrate difficulties learning to read, should be referred to reading specialists such as educational psychologists for evaluation for language processing disorders such as dyslexia. There is not adequate scientific evidence to suggest that "defective eye teaming", and "accommodative disorders" are common causes of educational impairment. Hence, routine screening for these conditions is not recommended.

Many serious ocular conditions that can be found at screening are treatable, if identified in the preschool and early school-aged years. Many of these conditions are associated with a positive family history. Additional screening emphasis should, therefore, be directed to high risk infants and children with a low threshold for obtaining a comprehensive eye examination by an ophthalmologist.

Appendix C

Sample Evaluation and Assessment Reports for Infants and Toddlers with Visual Impairment

1. Ophthalmologic Evaluation Reports

Report 1-a: John Brown

Report 1-b: Tommy Jones

Report 1-c: Lizzy Scott

2. Functional Vision Assessment (FVA) Reports

FVA 2-a: Becca Anderson

FVA 2-b: Dain Blacksmith

3. Sample Form Letter to be Completed by Ophthalmologist (to help document a child's visual impairment)

1-a. Ophthalmologic Evaluation Report: John Brown

Glaucoma Consultants Southeast

ophthalmic consultation

August 15, 2004

Re: John Brown
C.A. 10 months

John Brown had infantile cataracts which were removed in the first two weeks of life. He subsequently developed severe intractable glaucoma unresponsive to usual surgical methods. He has now had a drainage tube operation performed in each eye and at last the intraocular pressure seems to be reasonably well controlled.

During all of this time the corneas had become cloudy and they are just now beginning to clear again. The baby has nystagmus and at the moment it is uncertain the degree of vision that he has or in fact even his potential vision.

At the time of his next examination under anesthesia a hearing test is planned to evaluate that sensory modality.

Yours sincerely,

Robert Smith, M.D.

Robert Smith, M.D.

1-b. Ophthalmologic Evaluation Report: Tommy Jones

Aimon I. Dock, M.D., P.S.

Eye M.D.s of Timbuktu, P.L.L.C.

November 15, 2003

RE: Tommy Jones (DOB: 08/15/01)

Information is requested with regard to Tommy Jones. Tommy has been followed at this office for his eye exams after he was discovered to have isolated choroidal and iris colobomas at the time of birth.

Tommy was an extreme premature, born in the 27th week, with a birth weight of only 1 lb., 5 oz. He did not develop retinopathy of prematurity. However, he had bilateral typical iris colobomas and extensive choroidal coloboma involving both disc and macula of each eye. There appear to be no other significant congenital abnormalities, and accordingly the colobomas were felt to be isolated and not related to CHARGE syndrome. There is family and therapy concern as to his visual potential.

Tommy Jones can fixate and follow objects in his environment, and therefore is a visual person. However, his fixation is eccentric, in that he tends to observe objects by fixating above them, and his eyes appear to wander and rove with low frequency coarse nystagmus. The eyes are externally unremarkable, white and quiet. His eye motility is intact, but there is a variable small esotropia. The anterior segment structures are normal with the exception of the typical iris colobomas. His intraocular media is normal, and specifically there is no cataract. Fundus exam is abnormal. There are huge inferior choroidal colobomas which involve the optic nerve and macula of each eye.

There is no medical treatment for the congenital defects of choroidal coloboma. In Tommy's case, the coloboma is rather marked, and appears to have involved both the optic nerve and macula. As a result, he has developed a searching nystagmus, indicative of bilateral vision loss, severe. I suspect that his acuity will be sufficiently impaired that he will be statutorily blind, but will have sufficient visual function to be ambulatory. I hope this information is helpful in your assessment.

In addition, he is myopic, at -7.50 D, and a trial of glasses was recommended. He will return periodically.

Sincerely yours,

Aimon I. Dock, M.D.

Aimon I. Dock, M.D.

1-c. Ophthalmologic Evaluation Report: Lizzy Scott

Ophthalmology Consultation

Lizzy Scott is a 4 month old seen in ophthalmologic consultation at the request of Robert Smith, M.D., to evaluate poor visual development and to rule out possible cataract. The infant is new to our area, parents having moved here from Canada. The infant developed respiratory distress and was admitted with bronchiolitis requiring antibiotics and while admitted was discovered to have failure to thrive, a TE fistula, poor vision and dysmorphic features, all of which are being worked up. The nurses have noted that the infant does not track well, does not fixate, has spasms of dysconjugate gaze and has a watery and mattery left eye.

Examination is performed following pupillary dilation with 1% Mydracyl. Each eye has a light avoidance reflex. The lids and external ocular adnexa are unremarkable with the exception of an increased tear film in left eye and a modest mucopurulent discharge. The globes appear of normal size and are white and quiet.

Extraocular motility reveals full ductions but frequent spasms of dysconjugate gaze, mostly consisting of episodes of variable esotropia and variable superduction, often with transient skew deviation. In addition, there is a slow pendular roving nystagmus. The anterior segment structures are essentially unremarkable. The cornea is clear. The anterior chamber is formed. The iris appears normal with no inferior coloboma. There are a few persistent pupillary membrane strands. The media is clear with no evidence of cataract.

Fundus examination is abnormal. Using the indirect ophthalmoscope, it can be seen that there are huge bilateral colobomas which involve the entire inferior fundus from the far periphery back to the optic nerve, extending superior to the optic nerve and including the macular. The optic nerve itself is highly dysmorphic and features cannot be recognized. There are pockets of scleral ectasia throughout the coloboma but no marked staphyloma formation. The peripheral retina is flat with detachment.

IMPRESSION:

1. Bilateral choroidal colobomas, extensive, with secondary visual disability, marked, nystagmus and dysconjugate gaze.
2. Nasolacrimal duct obstruction, left eye, suspected.

COMMENTS: This infant has a congenital coloboma, extensive, involving the choroid macula and optic nerve of each eye. The exact degree of vision loss is speculative but will be severe, and the child will be statutorily blind. There is no specific ophthalmologic treatment for this condition and the only suggestion is that there be a genetics workup to

include such abnormalities as CHARGE syndrome. Ophthalmologic follow up will be important to gauge the infant's visual development and suggest that office follow up would be in three to four weeks if condition and social circumstances permit though could be somewhat longer if needed.

Many thanks for this consultation.

Dictated & Authenticated By:

Robert Smith, M.D.

Robert Smith, M.D.
Ophthalmology

2-a. Functional Vision Assessment Report: Becca Anderson

Child's Name: Becca Anderson

Parent(s)' Name: Gretchen

Date Of Birth: 6-30-02

Chronological Age: 14 months old

Dates of Visits: 7-7-03, 8-11-03, 8-22-03

Assessed By: Terri Smith (Infant Educator/ Teacher of the Visually Impaired)

Date of Report: 8-31-03

Background Information:

Becca is a fourteen-month-old little girl residing with her parents and brothers and sister in the Exemplary School District. The Family Resources Coordinator, in response to conversations with Becca's parents, requested that a functional vision assessment be completed in order to appropriately determine and plan for Becca's visual needs.

The goal of a functional vision assessment (FVA) is to determine what and how the child sees, and what can be done to best facilitate learning through the visual sense. The information that is gathered from a FVA typically includes information from the clinical vision evaluation performed by an optometrist or ophthalmologist, information from parent interview, and direct and indirect child observation and assessment by a certified teacher of the visually impaired.

Becca's mother, Gretchen, provided the following medical and developmental information: Becca was born five weeks prematurely. At that time she was diagnosed with bradycardia, myelomeningocele, and hydrocephalus for which she was shunted. She receives nutrition through a g-tube. In January of 2003, Becca was evaluated at Children's Hospital, Seattle, Ophthalmology Clinic, and in March of 2003, she was evaluated by a developmental optometrist. At that time she was diagnosed with alternating esotropia (turning in of one eye), and hyperopia (farsightedness). Glasses were prescribed as well as a series of activities to increase Becca's use of both eyes together in response to a variety of stimuli.

Mother filled the glasses prescription; however, she does not put the glasses on Becca for several reasons. The ear pieces seem to press on Becca's shunt site and because of her lack of head control when she is in supported sitting, the glasses are often pushed to one side of her face. The family feels that Becca doesn't respond to her visual environment any differently when wearing the glasses.

Observation Findings

The functional vision evaluation was completed during three home visits in sessions of 90 minutes each. Direct child observation and interaction as well as parent interview were used. Becca remained attentive during each session with short breaks about

every twenty minutes. Assessment took place in various rooms in the family's home. Lighting varied from natural lighting from windows to dimmed lighting in a windowless room, as well as total darkness with only a flashlight.

Becca's eyes were clear, bright and free of matter. A slight turning in of each eye was noted (alternating) depending on the distance of object to be viewed and its location. There was no evidence of nystagmus during these observations.

Becca alerted to stimuli presented in her periphery, then moved her head and eyes to the object. Initially, there was a response latency of about 30 seconds. By the third visit she responded within seconds. Mother commented that she felt Becca had been responding more quickly over the past few weeks.

The best field of vision for Becca appears to be below the visual horizon, and from 45 degrees on the left to 45 degrees on the right. She visually fixed on objects entering her periphery and used her head and eyes to follow the object from left to right and right to left. Her tracking was awkward, but she was able to relocate the object and continue if the object moved slowly and stopped when she lost sight of it. Becca was able to follow an object moving vertically from below the visual horizon to above her eyes by using a blink strategy to move her eyes up. At one point her brother walked by at a distance of about 5 feet. Becca followed his movement, which entailed following him visually from left to right and then turning her head and eyes to follow him moving behind her. She also was observed shifting her vision from an object in front of her to her sister, who was lying down in front of her.

Becca alerted to pictures presented in a variety of positions within her visual field. She responded and maintained a visual fixation the longest when the picture was held in the lower left quadrant of her visual field at about 10 inches. Pictures used had a reflective quality, high contrast color, or were black-on-white silhouettes.

Observation of Becca's visual skills without any attempt to elicit a response revealed that she turns to sound, locates object, person (face) and visually fixes at about 10 inches. Often it appeared that she was using her right eye and her left eye turned in. Becca also leads with touch, then looks at the object she has touched. Her mother, Gretchen, feels that Becca depends a great deal on touch to alert her to things that may be interesting to look at. It seems that she may be visually aware that an object is in her visual field, and rather than locating the object visually then reaching for it, she catches sight, reaches to touch, then looks at the object she has touched.

Observation of Becca's visual responses was conducted in a variety of lighting environments. There didn't seem to be any advantage to making the environment darker and the stimulus brighter. Becca responded faster and with more interest to things that were interesting to her, e.g., family members, rather than to a specific degree of lighting. Gretchen feels that there is a need for some ambient lighting in order for Becca to be visually interested.

Becca was placed in a variety of positions that allowed for her to maintain some head

control and use her eyes with a minimum of expended energy. When positioned in side lying in my lap, she was able to maintain a flexed, relaxed position and use her left arm to reach out and activate a toy. Another good position for her to maintain control and use her eyes to follow her reach is in her mother's lap, leaning against her chest with a boppy pillow on her lap supporting her shoulders. The toy is then placed to the right of midline for her to activate.

Significance of Findings Relative to Instructional Programming:

Becca continued to make visual progress throughout the evaluation sessions. The majority of the evaluation took place with her glasses off. She demonstrates a visual interest in her environment, and attempts to reach for objects and bat at toys she sees. She visually fixes on pictures that are simple and of high contrast. The greatest assist to her visual organization is her positioning. It is critical that she be positioned in such a way that allows her postural security and minimizes loss of head control when she is attempting to use her vision. Motion of object when presented and presentation somewhere off of midline seems to help her locate the object. At one point there was a difference in response noted with her glasses on versus off. With her glasses off we had to get within 4" of her face for her to make eye contact. With her glasses on, the same response was noted at 12".

Recommendations:

1. Becca should continue to be monitored by her developmental optometrist.
2. A certified teacher of the visually impaired should be a part of Becca's early intervention team. The role of this professional would be to act as a consultant to the team regarding the impact Becca's vision impairment will have on her development and strategies that will assist her learning.
3. At this point in time the most appropriate environmental setting for Becca to help her visually interpret her world would be an environment that has some ambient lighting, using toys with a reflective quality or high color contrast.
4. Her physical positioning when asked to use her eyes is critical. Becca needs to be comfortable, posturally secure, and supported in such a way that she is capable of using the visual skills she has. She will not be able to organize her vision if she is not organized posturally.
5. "Looking" is an extremely fatiguing activity, especially for children with additional motor involvement. Allow Becca opportunity to visually rest. There will rarely be a waking time when she is not attempting to use her vision. Letting her "check out" for a while then come back to something visually interesting provides a good learning environment, rather than perceiving looking as a task that has to be performed so many minutes per day.
6. Time is a critical component for Becca's visual success. She will need more time to

locate, process and respond to visual stimuli. It is not too long to wait a minute for her to begin her involvement with a task. Slow is the name of the game.

Thank you for the opportunity to meet Becca and her family. If you have any other questions or I can be of any further assistance, please call.

Terri Smith

Terri Smith, M.S., Vision Consultant
Infant Educator/ Teacher of the Visually Impaired

2-b. Functional Vision Assessment Report: Dain Blacksmith

Child's Name: Dain

Parent(s) Name: Ms. Blacksmith

Date of Birth: 02-09-03

Chronological Age: 22 months old

Dates of Visits: 8-7-03, 9-11-03, 9-22-03

Assessed By: Mark Jones (Teacher of the Visually Impaired)

Date of Report: 9-30-03

Background Information:

Dain and his mother, Ms. Blacksmith, recently moved to Fern County. Ms. Blacksmith provided medical information, since Dain's medical reports are still packed. She reported that Dain was diagnosed with septo-optic dysplasia*. Dain reportedly has better vision in his right eye, and "not much vision, if any, in his left eye." Results of an MRI indicated a missing septum pellucidum (which forms the medial wall of the lateral ventricles of the brain). His hearing has not been tested.

Observation Findings:

The functional vision assessment (FVA) was completed over three separate visits to the home. The purpose of a FVA is to complement the ophthalmologist's clinical findings in order to give the best picture of a child's visual skills and to help determine what changes in his environment may be necessary to maximize his visual potential.

This assessment took place in the home of Dain's grandparents. The play environment consisted of the living room, dining room/kitchen, and hallway. The lighting during the assessment came from a large picture window in the living room. Overhead lighting was available in the kitchen/dining area.

Evaluation of Dain's eyes revealed clear, unmatted eyes with no redness or crustiness. He exhibited nystagmus. When his right eye fixed on a face or object, his left eye turned inward. Dain is a visually alert little boy. He turns to look for people he hears entering the room. He glances from a toy he is playing with to visually fix on someone entering his field of vision. His near vision skills were demonstrated by his completing a three-piece shape sorter (dropping objects into a clear plastic container), a task that required him to reorient the object to fit in a narrow slit on the lid. Both of these toys had contrasting surfaces for him to find the correct shape and slit respectively. He was able to retrieve two-inch diameter rings from a flowered carpet if the rings were of a high contrast. He missed picking up the rings that were close in color to those in the carpet.

* A condition associated with optic-nerve hypoplasia, which is manifested in the form of an underdeveloped optic nerve in one or both eyes. In septo-optic dysplasia, there also are absent or poorly formed parts of the brain, often associated with hormone deficiencies.

Summary:

Dain was a joy to observe. He demonstrated an interest in and enthusiasm for toys and people in his environment. He was very aware of happenings in his surroundings and was able to ascertain who came and who left his presence. Based on parent input and direct observations, it is my impression that Dain compensates efficiently for his vision impairment. He demonstrated a variety of visual and tactile strategies to assist in acquiring information about his environment. The poorer vision in his left eye presents a barrier for his eyes working together. For example, his lack of binocular vision was evidenced in the difficulty he had placing a ring on a post and stacking blocks. This may present more of a problem now that Dain is walking, especially when he needs to determine changes in elevation.

Global Recommendations:

It is recommended that:

1. Dain continue to be monitored by a pediatric ophthalmologist.
2. Dain be evaluated audiologically to rule out a hearing impairment. Due to his medical diagnosis of septo-optic dysplasia, he is at high risk for hearing loss.
3. Dain and his early intervention team receive regular consultation services from a teacher of the visually impaired, on a schedule to be determined by the team.
4. Dain receive an orientation and mobility evaluation conducted by an orientation and mobility specialist.

Specific Early Intervention Program Implications:

- While Dain did well visually with traditional lighting in his home, in unfamiliar settings he may need to take advantage of lighting that is directly on the task at hand. Lighting needs to be a consideration in all of his environments, both indoors and out. Lighting outside can often cause a travel route to be deceptive, for example, light through leaves on a tree may cause the ground to look as if there is a surface change, and too bright a day may diminish his usually good visual skills.
- Dain responded best to objects that were located on a high contrast background. It is important to look beyond the object or task he is working on to see if the background is visually cluttered or very close to the same color as the target object.
- Allow Dain to use his vision and hold objects any way that best suits his ability to obtain accurate information, e.g., holding his books close to his face to locate specific pictures in the book. This has great implications during a preschool group time, for example, Dain will not benefit from reading in circle time where there is one book and the teacher holds it. It would be best if he were allowed to

have a copy of the same book to look at the pictures and follow along. This is true of most circle activities where the object to be viewed is at a distance.

- Time is a crucial component for children with a visual impairment. They need time for hands-on inspection of tasks they are expected to accomplish before they begin the task. This applies to both table tasks and gross motor tasks. If Dain is expected to follow a direction or imitate a task before he has had time to inspect the situation, he may balk at participating.
- For children with visual impairments, looking is a very fatiguing task. It is advisable to allow Dain to change from a task requiring visual concentration to a task that requires listening only or some other more relaxing activity. After a brief rest he can return to more challenging visual tasks.

Please let me know if there are any questions about the contents of this report.

Mark Jones

Mark Jones, M.S., Vision Consultant
Teacher of the Visually Impaired

3. Sample Form Letter to be Completed by Ophthalmologist
(to help document a child's visual impairment)

Date: _____

To: _____

From: _____

Address: _____

Re: _____ B.D. _____

Your patient, _____, is being evaluated to determine eligibility and need for early intervention services. Your evaluation will help determine the services this child receives. It is important that if a child has a visual impairment that is significant enough to make an impact developmentally and/or educationally, it be documented.

Please complete this form and return to above address. If you have any questions please call me at: _____. Thank you for your assistance.

Sincerely,

(Name)

Family Resources Coordinator

(To be completed by ophthalmologist:)

I agree that this child demonstrates a visual impairment that will significantly impact his/her development.

Physician's Signature

Date

Comments:
