



Visual Impairments

Service Delivery Guidelines

Intervention guidance for service providers and families of young children
with vision impairments



State of Alaska • Department of Health & Social Services • Office of Children's Services
Alaska Early Intervention • Infant Learning Program

ALASKA EARLY INTERVENTION / INFANT LEARNING PROGRAM

Service Delivery Guidelines

VISUAL IMPAIRMENTS

INTERVENTION GUIDANCE FOR SERVICE PROVIDERS AND FAMILIES
OF YOUNG CHILDREN WITH VISUAL IMPAIRMENTS

JUNE 2011



MISSION

To promote positive development and improved outcomes for Alaska's families by creating a culturally responsive, comprehensive and accessible service delivery system that links service providers, empowers families and engages communities

–Alaska Early Intervention/ Infant Learning Program

SERVICE DELIVERY GUIDELINES FOR ALASKA

VISUAL IMPAIRMENT

Alaska Early Intervention/Infant Learning Program

June 2011

Erin Kinavey, Early Intervention Manager - Part C Coordinator
Lisa Balivet, Data Manager
Meghan Johnson, Training Coordinator
Linda Borghols, Program Specialist
Jane Atuk, Program Specialist
Kassi Hill, Office Administrator

Acknowledgments

The Alaska Early Intervention/Infant Learning Program would like to thank the following people for their personal and professional contributions to the completion of this guide.

Kristin Bradshaw, MS, OTR/L – Alaska Center for Children & Adults (ACCA)
Jacinda Danner, MEd – AVISION / Mat-Su Borough School District
Amanda Faulkner – Frontier Community Services
Kimala Rein – Programs for Infants & Children (PIC)
Lizette Stiehr, MA – Family Outreach Center for Understanding Special Needs
(FOCUS)
Andrea Story – SESA (Special Education Service Agency)

Prepared by

Information Insights, Inc.
212 Front Steet, Suite 100
Fairbanks, Alaska 99701
(907)450-2450
www.iialaska.com

CONTENTS

Introduction.....	5
Understanding Visual Impairment	7
Screening for Visual Impairments.....	14
Assessing Visual Impairments.....	18
Approaches to Intervention	25
Planning for Transition	31
References	33
Appendices.....	35

INTRODUCTION

“The primary difference between children with and without visual disabilities is not what they learn, but how they learn.” — Kay Alicyn Ferrell

Many children experience poor eyesight. For most, corrective lenses allow them to pick up a toy, focus on a caregiver’s face, and process all the visual stimuli around them. For only a very small number of children (one half of one percent of the school age population in the U.S.¹) are visual impairments significant enough to put them at risk for development delays.

Sight is used to regulate the other senses. A sighted child will see an object and reach for it in order to explore it with hands or mouth. A child with a visual impairment may need to have the object placed in his or her hands to reinforce this type of exploration and experiential learning. Children with visual impairments can learn the skills sighted children learn, but they will learn them differently.

PURPOSE OF THE GUIDELINES

The purpose of these guidelines is to provide parents and service providers with an overview of the best practices for early intervention for young children referred for vision impairments in Alaska. These include those approaches shown to result in the best outcomes for children from birth to three.

While most of the recommended practices in the guidelines do not carry the force of regulation, they are intended to guide parents and providers in making informed decisions about the most appropriate assessment practices and intervention strategies for young children. They provide information on transitioning to school- and community-based services when a child approaches age three. Resources for obtaining more information and support are listed in the appendices.

Not all practices will be appropriate in all cases. The guidelines are intended to be flexible, not prescriptive or limiting, and to set the tone for the family to be an instrumental part of early intervention. An Individualized Family Service Plan (IFSP) should be developed for each child based on his or her particular needs, the resources available, and input from the family and the early intervention provider or team.

¹ Numbers are not available for the birth to three population.

EARLY INTERVENTION SERVICES IN ALASKA

Early intervention services are federally mandated under Part C of the Individuals with Disabilities Education Act (IDEA), a federal law passed in 1986. IDEA requires states to ensure that young children who may have disabilities or developmental delays receive an evaluation to identify the potential need for early intervention. Alaska's early intervention services are administered by the Department of Health and Social Services, Office of Children's Services, Early Intervention/Infant Learning Program (EI/ILP). They include a flexible array of services for children birth to 3 years of age who experience disabilities or developmental delays, or who are at risk for developmental delays.

EI/ILP partners with grantees to provide services directly to families at a local and regional level. In 2010, services were provided to children throughout the state by approximately 115 highly qualified staff employed within 17 regional grantee agencies. Programs vary widely by staff and region size. Service may include:

- Developmental screening and evaluation
- Individualized Family Service Plans to outline goals for the family and child
- Child development information
- Home visits
- Infant mental health services
- Physical, occupational or speech therapy
- Specialized equipment
- Referrals to other needed services

EI/ILP Approach to Service Delivery

Because no single professional can meet all the needs of a child with developmental delays, EI/ILP encourages the use of a *transdisciplinary* approach, with a primary service provider assigned to each child and a team of professionals from different disciplines who share their expertise with the parents and other team members as needed to support the child's progress and participation in daily activities in the family's home and community. In addition to taking a team approach to service delivery, the core values of EI/ILP support services that are *evidence-based* and *family-centered*. By listening to the family throughout the process, intervention techniques can be modified on a continual basis to match the child's and family's unique needs and strengths.

More Information

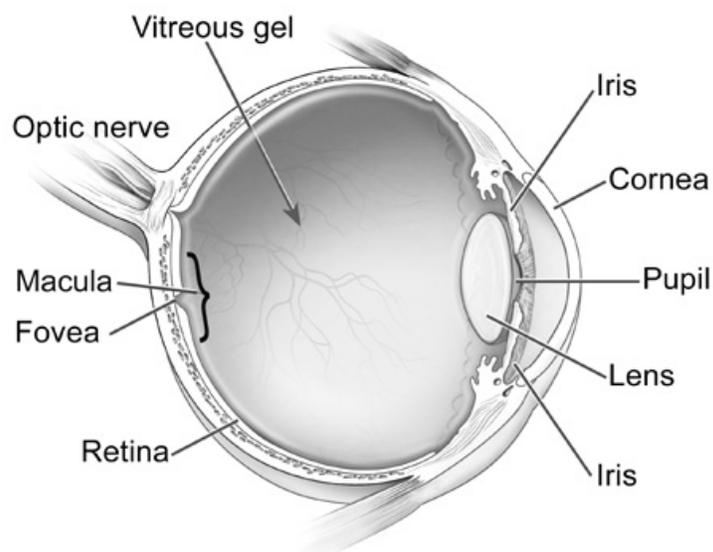
More information and resources for early intervention services in Alaska are available at the EI/ILP website. The site includes a statewide directory of EI/ILP programs that cover all regions of the state.

 www.earlyintervention.alaska.gov

UNDERSTANDING VISUAL IMPAIRMENT

Vision can be compromised in a variety of ways. An injury, disease or a congenital or genetic defect may damage the eyes themselves, or the optic nerve may be damaged, which can affect the information going to the brain even if the eyes themselves are healthy and functioning correctly. Finally, the brain may be affected as a result of congenital or genetic conditions, injury or disease, and vision can be impaired as a result.

Few people are truly blind; most have some sight or light perception, allowing them to see shadows or forms. Visual Impairment is a term that describes the wide range of types and severity of vision loss, which can include a loss of peripheral vision, loss of central vision or an overall loss of acuity.



TYPICAL VISION DEVELOPMENT

Vision is a combination of healthy eyes working together and with the optic nerve to send information to the brain. Vision and a child's development are inextricably linked. While a newborn's eyesight is not fully developed, babies begin using their eyes almost right away to sort, understand and learn about world around them. When a baby's vision is not developing typically, it changes the way he or she interacts with the environment.

The following developmental milestones describe typical vision development in infants and toddlers, as outlined by the American Optometric Association (1),

Birth to 4 months

- A newborn's focus is on objects about 8 to 10 inches from his or her face (the distance to a parent's face). Newborns may also look intently at a highly contrasted target.
- During the first months of life, the eyes start working together and vision rapidly improves. Eye-hand coordination begins to develop as the infant starts tracking moving objects with his or her eyes and reaching for them. By 8 weeks, babies begin to more easily focus their eyes on the faces of a parent or other person near them.
- For the first 2 months of life, an infant's eyes are not well coordinated and may appear to wander or to be crossed. This is usually normal. However, if an eye appears to turn in or out constantly, an evaluation is warranted.
- Babies should begin to follow moving objects with their eyes and reach for things at about 3 months of age.

5 to 8 months

- During these months, control of eye movements and eye-body coordination skills continue to improve.
- Depth perception, which is not present at birth, begins at about the fifth month, when the eyes are capable of working together to form a three-dimensional view of the world.
- Although an infant's color vision is not as sensitive as an adult's, it is generally believed that babies have good color vision by 5 months of age.
- Most babies start crawling at about 8 months old, which helps further develop eye-hand-foot-body coordination. Early walkers who do minimal crawling may not learn to use their eyes together as well as babies who crawl a lot.

9 to 12 months

- At about 9 months of age, babies begin to pull themselves up to a standing position. By 10 months of age, a baby should be able to grasp small objects with thumb and forefinger.
- By 12 months of age, most babies will be crawling and trying to walk. Parents should encourage crawling rather than early walking to help the child develop better eye-hand coordination.
- At 12 months of age, babies can judge distances fairly well and throw things with precision.

12 to 24 months

- By 2 years of age, a child's eye-hand coordination and depth perception should be well developed.
- Children this age are highly interested in exploring their environment and in looking and listening. They recognize familiar objects and pictures in books and can scribble with crayon or pencil.

LEADING CAUSES OF VISUAL IMPAIRMENT

“Vision is not a single sense, but a combination of complex senses which have evolved over millions of years. Almost the entire brain is involved in the processes of seeing.”
– American Printing House for the Blind

Visual impairment is a functional loss of vision resulting from either disease, trauma, or congenital or degenerative conditions that cannot be corrected by conventional means, such as refractive correction (eye glasses or contact lenses), medication or surgery. The leading causes of visual impairment in young children are cortical (cerebral) visual impairment (CVI), retinopathy of prematurity (ROP), optic nerve hypoplasia (ONH), optic nerve atrophy (OA), albinism, and other retinal disorders.

CORTICAL VISUAL IMPAIRMENT OR CEREBRAL VISUAL IMPAIRMENT (CVI)

Cortical Visual Impairment is the fastest growing visual impairment diagnosis (2). CVI is a neurological visual disorder that results in inconsistent or reduced vision as a result of brain abnormalities. Different areas of the brain specialize in distance vision, recognition of faces, objects, colors, contrast and movement. Additionally, there are areas of the brain for coordinating visually directed movements and processing visual information such as direction and depth. CVI is the result of widespread damage to the brain, affecting most of the visual centers resulting in impaired vision. It is important to note that CVI is not an indication of the child's cognitive ability (3).

Damage to the brain can be caused by a wide variety of brain insults including:

- Lack of oxygen during the birth process (asphyxia, hypoxia, ischemia)
- Developmental brain defects
- Cerebral palsy
- Head injury
- Hydrocephalus (excess cerebrospinal fluid in the brain causing pressure)
- Stroke
- Infections affecting the brain (meningitis and encephalitis)(3)

Children with CVI will likely have a normal or near normal eye examination, a medical history which includes neurological problems and the presence of unique visual and behavior characteristics (2):

- **Normal or minimally abnormal eye exam.** CVI may co-exist with optic nerve atrophy, hypoplasia or dysplasia and ROP.
- **Difficulty with visual novelty.** The individual prefers to look at old objects, not new, and lacks visual curiosity.
- **Visually attends in near space only**
- **Difficulties with visual complexity/crowding.** Individual performs best when one sensory input is presented at a time, when the surrounding environment lacks clutter, and the object being presented is simple.
- **Non-purposeful gaze/light gazing behaviors**
- **Distinct color preference.** Preferences are predominantly red and yellow, but could be any color.
- **Visual field deficits.** It is not so much the severity of the field loss, but where the field loss is located.
- **Visual latency.** The individual's visual responses are slow, often delayed.
- **Attraction to movement, especially rapid movements**
- **Absent or atypical visual reflexive responses.** The individual fails to blink at threatening motions.
- **Atypical visual motor behaviors.** Look and touch occur as separate functions, e.g., child looks, turns head away from item, then reaches for it.
- **Variable vision throughout the day.** The vision of a child with CVI is quite variable, due to fatigue, illness, hunger, lighting changes etc.

RETINOPATHY OF PREMATURITY (ROP)

Retinopathy of Prematurity or ROP is an ocular disorder that affects premature infants. It occurs when abnormal blood vessels grow and spread throughout the retina, the tissue that lines the back of the eye. These abnormal blood vessels are fragile and can leak, scarring the retina and pulling it out of position. This causes a retinal detachment. Retinal detachment is the main cause of visual impairment and blindness in ROP (4).

This abnormal growth occurs within weeks of birth. Once the development of blood vessels is complete, the child is no longer at risk for ROP if they have not already developed it (3). The cause of ROP is not entirely understood, but it is believed that it is the result of complex factors happening in the development of the eye. According to the National Eye Institute, the eye begins to develop at about 16 weeks gestation, with the retina blood vessels forming the optic nerve in the back of the eye. These blood vessels slowly grow toward the edges of the developing retina, supplying oxygen and nutrients. The eye begins to develop more rapidly during the

last 12 weeks of a pregnancy. When a baby is born full-term, the retinal blood vessel growth is mostly complete. Scientists believe that prematurity stops the normal growth of the blood vessels, and the edges of the retina (the periphery) may be starved for nutrients and oxygen. The lack of nutrients and oxygen may result in the tissue sending out signals to other areas of the retina for nourishment, resulting in new abnormal blood vessel growth (4).

Medical advances have increased the ability of smaller and more premature infants to survive. However, these infants are at a higher risk for ROP, with the risk being the greatest among infants born with birth weights less than 2.75 pounds (1250 grams) or less than 31 weeks gestation. Each year between 14,000 and 16,000, or a little over half of those extremely premature infants, develop some level of ROP. Fortunately, about 90 percent of those remain in the more mild stages of the disease and recover without treatment. However, infants with more severe disease can develop impaired vision or even blindness. Approximately 1,100 to 1,500 infants annually progress to a level of severity requiring medical treatment, and about 400 to 600 of these infants become legally blind (4).

ROP is classified in five stages, ranging from mild (stage I) to severe (stage V). While only a small percentage of premature children reach the higher stages of the disease, medical evaluation is critical to monitoring the severity of the condition, even after they are released from the hospital.

Unique visual and behavioral characteristics among children with ROP include:

- At risk of developing other eye problems later in life (cataracts, glaucoma, retinal detachment, myopia, strabismus, amblyopia etc.)
- May have other impairments (normally associated with extreme prematurity) such as CVI, cerebral palsy or learning disabilities
- May use unusual body positions to see better
- May lose distance sight and peripheral vision (5)

OPTIC NERVE HYPOPLASIA (ONH)

Optic Nerve Hypoplasia (formerly known as Septo Optic Dysplasia) is the result of a problem with the development of the optic nerve during early pregnancy. ONH may occur in one eye (unilateral) or, more commonly, in both (bilateral). It is not a genetic or inherited condition. What causes the optic nerve to not fully develop in these children is not fully known (6). ONH can be diagnosed by a qualified medical eye care specialist who can exam the heads of the optic nerve.

There is a strong association with ONH and neurological and hormonal abnormalities. Children with ONH are at high risk for adverse outcomes associated with hypopituitarism, brain malformations, and delayed neuropsychological development (7). It is important that babies and toddlers with ONH be examined by an endocrinologist as soon as possible. However, the visual acuity is stable and does

not deteriorate over time. Children with ONH may experience a wide variety of visual function from normal acuity to blindness (no light perception). Visual fields may be affected in both a child's central and periphery vision. Children with ONH also experience involuntary rhythmic movement (nystagmus) at high rates.

Unique visual and behavioral characteristics of ONH include:

- The child's vision is characterized by a lack of detail (depressed field), not comparable to the blurred reduction in vision when a person removes her glasses.
- When a specific field defect occurs, a child may not be aware of people or objects in the periphery.
- A child with ONH may be unable to locate objects in space due to a lack of depth perception.
- Some children with ONH have mild photophobia. These children may squint, lower their head, avoid light by turning away, or resist participating in outdoor activities.
- When one eye is affected more than the other, an ophthalmologist may recommend a trial of patching the stronger eye, since the visual loss may be due to amblyopia.
- Some feeding issues are associated with hormonal problems. Lack of interest in eating may be due to absent or diminished sense of smell and taste. Children with ONH may have very restricted food preferences.
- Behaviors of some children with ONH may be due to associated medical conditions, such as inattentiveness and irritability due to low blood sugar levels (hypoglycemia).
- Some children with associated central nervous system problems may have other complications which can include being easily distracted, quickly frustrated and act in a disorganized or an impulsive way. (6)

ALBINISM

Albinism is not a single condition, but a group of genetic and inherited conditions in which a person produces none or very little melanin and has little or no pigment in the eyes, skin or hair. While inherited, albinism affects all races and occurs at the rate of 1 per 17,000 people in the United States. Using DNA analysis, researchers have identified four major types of albinism which range from producing no melanin (white hair and very light skin) to producing substantial pigmentation, including a rarer form of albinism called ocular albinism (OA) that only affects the eyes (8).

It is important to note that while hair and skin pigmentation vary greatly among children with albinism, all people with albinism have abnormal development of the retina and abnormal optic nerve connections. In fact, the main test for albinism is an

eye exam. Although the severity of vision problems may result in visual impairment, albinism does not result in a complete lack of light perception (total blindness), but rather in low vision (8).

While many people with albinism have lighter colored eyes, not all do. Eye color ranges from red or violet to blue, brown and hazel, and skin, hair and eye color alone are not diagnostic indicators of the condition.

In addition to low visual acuity (20/50 to 20/800), children with albinism are likely to experience sensitivity to bright light and glare (photophobia) and rhythmic, involuntary eye movements (nystagmus). They are also likely to lack stereo vision, may experience strabismus (one or both eyes crossing), and may be either farsighted or nearsighted, often with astigmatism. Because of the lack of pigment, people with albinism are significantly more sensitive to ultraviolet light and can develop cataracts later in life (9).

Visual and behavioral characteristics of children with albinism include:

- Infants with albinism may behave as if they are not seeing during the first weeks of life and gradually become visually attentive.
- Children bring objects close to their eyes to see more clearly.
- Even with glasses or contacts, vision will not correct to normal.
- Occasionally a child's eyes will look pink or red due to a reflection on the back of the eye (retina).
- Additional energy and effort a child uses to process visual information can cause fatigue and irritability, worsening nystagmus.
- Children typically exhibit an eye or head position (null point) that allows them to slow down or stop their nystagmus.
- Children may use one eye at a time for looking.
- Children may have an absence of stereo vision contributing to depth perception problems.
- Changes in lighting sources, position, and glare can have a significant influence on the child's ability to see. Children are slow to adjust to changes in lighting, such as from outdoors to indoors or sunny light to shadows. (9)

MORE INFORMATION

The Blind Babies Foundation publishes a series of factsheets on common visual diagnoses. The factsheets are intended for families, therapists, and medical and educational professionals who work with children with visual impairments. Topics include visual/behavioral characteristics, myths, teaching strategies, as well as information on eye specialists and vision assessments. Factsheets can be downloaded for free in English and Spanish from:



blindbabies.org/learn/diagnoses-and-strategies

SCREENING FOR VISUAL IMPAIRMENTS

All children being evaluated and assessed for EI/ILP services should have a vision screening. Early detection of significant vision loss allows EI/ILP to provide intervention earlier—reducing developmental delays and occasionally limiting vision loss. High risk infants (such as those born prematurely) should be examined by an ophthalmologist as early as possible.

Due to the increased risk for ROP, the American Academy of Pediatrics, the American Association for Pediatric Ophthalmology and Strabismus and the American Academy of Ophthalmology recommend the ophthalmological examination of premature newborn infants with birth weights less than or equal to 1,500 g and gestational ages less than or equal to 28 weeks when they reach 6 weeks postpartum.

The American Optometric Association recommends that all young children have their first comprehensive eye exam at about 6 months of age, even if no vision or eye problem is suspected. Subsequent eye exams should occur at 3 years of age and then again prior to first grade, around 6 years of age. However, if an infant is displaying any signs of visual impairment (or if a child develops any of signs of visual impairment at any time), the child should be seen by a qualified eye care specialist as soon as possible.

WHY IS EARLY IDENTIFICATION IMPORTANT?

It is absolutely critical that children with visual impairments be identified as early as possible. A normally developing child uses vision to “regulate” all the other senses. Without intervention a child will not gain skills at the same rate and runs the risk of being severely delayed. Rest assured, a child with visual impairment can gain these same skills, but will need to learn them in a different way.

Catching and preventing strabismus and amblyopia actually stops vision loss and, in many cases, can restore vision. Having two eyes that see well allows the child to see binocularly, giving them depth perception and gives them a greater chance at preserving their sight in later years, in case of accident or injury to the eyes.

SCREENING INFANTS AND TODDLERS FOR VISION CONCERNS

Early intervention service providers must ensure that infants and toddlers are screened for vision (and hearing) concerns within 45 days of referral to the EI/ILP program. If there is any concern after completing a vision screening, refer the child and family to a pediatric ophthalmologist for further evaluation. V.I.S.T.A. (Vision Impairment Screening Throughout Alaska), a comprehensive vision screening tool used by EI/ILP providers, is included in Appendix 1.

Note: While EI/ILP providers are required to screen eligible children for vision, these screenings are not diagnostic. Diagnosis must be provided by an ophthalmologist or optometrist.

Family Interview

Early intervention service providers and family members play a crucial role in identifying vision issues in infants whose visual disorders were not identified at birth. Parents are often the first to voice a concern about their baby's lack of eye contact or inability to track a moving object. They may describe the way their baby uses his or her vision as being "not quite right." EI service providers are in the unique position of helping to identify children who are participating in EI services but whose visual concerns have not yet been addressed and evaluated. They may do so by listening to parents, observing carefully, and supporting the family in getting further information from medical professionals when necessary.

Photoscreening

Photoscreening is a vision screening technique used to screen for amblyopia, strabismus, and significant refractive errors, in one or both eyes, that is especially promising in improving vision screening rates in infants, preverbal children, and those with developmental delays who are the most difficult to screen (10).

Using a camera or video system appropriately equipped for photoscreening, images of the pupillary reflexes (reflections) and red reflexes (Brückner test) are obtained. Other than having to fixate on the appropriate target long enough for the photoscreening, little cooperation is needed from the child. Data are then analyzed by a trained evaluator or computer for amblyogenic factors, and positive findings are noted. Children who do not pass the test may be referred for a complete eye examination.

The photoscreener must be used in conjunction with a full EI/ILP vision screen and should not be used by itself. Advantages of photoscreening include its ease of use with young children and its reliability in identifying possible visual concerns—provided the equipment operator has been well trained and has support for interpreting the photos.

However, this tool is not without its limitations. Most importantly, it does not identify all possible visual concerns, so over-reliance on it could cause some significant vision impairments (CVI for example) to be overlooked. Also, staff needs

to be trained to use the equipment effectively, and a cooperating ophthalmologist needs to help interpret the photos. AAP guidelines for the use of photoscreening as a technique for the detection of amblyopia and strabismus in children of various age groups can be found in the March 2002 issue of *Pediatrics* (10).

ELIGIBILITY FOR EI/ILP SERVICES

While some children are born with vision impairment as their only developmental concern, most have at least one other area of delay or disability (11). Identifying a vision concern when a child has other developmental delays can be difficult. It is important to do so, however, because vision impairment of any kind can have a profound impact on a child's development.

It is also important to note that not all visual conditions qualify a child for EI/ILP services from a Teacher of Students with Blindness or Visually Impairment (TVI) or an Early Childhood Teacher of Students with Blindness or Visually Impairment (ECTVI). For example, eye muscle disorders such as strabismus, near-sightedness or far-sightedness that can be corrected by glasses, or a visual impairment in one eye with normal vision in the other, do not typically require TVI services.

Common Visual Disorders

The following list includes the most common visual disorders that generally qualify an infant or toddler for EI/ILP services that may include consultation or direct vision services from a TVI or ECTVI. This is not an exhaustive list. Children's needs for vision services must be assessed on an individualized and ongoing basis. It is important to note that the child may qualify for visual impairment services (direct or consultation) when one of the following conditions is present, combined with low vision (visual acuity of 20/70 or worse in the better eye or a visual field loss reducing combined visual field to 20 or less):

- Albinism
- Bilateral congenital cataracts
- Bilateral Peter's anomaly
- CVI (Cortical vision impairment or cerebral vision impairment)
- Glaucoma
- Leber's congenital amaurosis/Retinal dystrophy
- Microphthalmia
- Nystagmus, congenital
- Optic atrophy
- Optic nerve hypoplasia
- Retinal detachment
- CHARGE association (when accompanied by significant colobomas)
- Cytomegalovirus (CMV), if it results in vision loss

- Coloboma
- Delayed visual maturation
- DeMorsier's syndrome
- Down syndrome (with high myopia)
- Retinoblastoma
- Retinopathy of prematurity

These conditions often result in a visual impairment of a degree that will qualify an infant or toddler for vision services of a consultative or direct nature. EI/ILP service providers should be alert for these terms in a child's medical history or during interviews with parents and caregivers (12).

ASSESSING VISUAL IMPAIRMENTS

Infants and toddlers with visual impairment who have been referred to early intervention services need a comprehensive approach to evaluating and assessing their developmental needs. Please note, it is important that a child with visual impairment be assessed and evaluated by a qualified TVI or ECTVI due to the significant differences in testing needs (with appropriate adaptations made for specific items on the assessment tools that require vision to perform). Each developmental area needs to be evaluated:

- Cognitive
- Physical (including vision, hearing, fine and gross motor)
- Social-emotional
- Adaptive
- Communication/language

VISION ASSESSMENT PROCEDURES

In addition to the evaluations listed above, a complete picture of the child's visual status needs to be assessed in order to develop IFSP and complete program planning. Complete evaluation or assessment should include results of a *functional vision assessment (FVA)*. A *learning media assessment (LMA)* and an *orientation and mobility evaluation (OME)* should also be included, if developmentally appropriate. The information from each of these areas is critical but different in the goals addressed.

Below are brief descriptions of several different procedures that are typically carried out with infants and toddlers prior to and following diagnosis of a visual impairment.

PEDIATRIC OPHTHALMOLOGIC EVALUATION

The goal of the ophthalmologic evaluation is to diagnose and determine a treatment plan to preserve and enhance vision. This examination takes place in the ophthalmologist's office and may take from 15 to 60 minutes.

In its 2001 Policy Statement, 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

toddlers be screened for visual problems as follows, and any child who does not pass these screening tests should have an ophthalmologic examination:

- 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 neurodevelopmental delay also should be examined by an ophthalmologist.
- All infants by 6 months to 1 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.

Please note: Because of a higher incidence of vision impairments in children who are deaf or hard of hearing, infants and toddlers who have been diagnosed with a hearing loss should have a vision evaluation.

FUNCTIONAL VISION ASSESSMENT (ESSENTIAL ASSESSMENT)

Once an infant or toddler has been diagnosed with a visual impairment, completion of a functional vision assessment is one of the primary roles of the TVI or ECTVI. The goal of the functional vision assessment, done in collaboration with the IFSP team, is to determine what and how the child sees, and what can be done to best facilitate learning through the visual sense. This assessment accomplished in the child's home, childcare facility, and/or other community setting and typically requires several visits over a period of time. During the child's first years, functional vision assessments need to be reviewed several times since vision can fluctuate over time.

The information that is gathered from a FVA is quite different from what is gathered from a clinical vision evaluation at a doctor's office, in that it is not diagnosis or treatment oriented. The goal of a FVA is to determine the child's visual strengths and needs, and to develop strategies for optimizing and/or promoting the use of visual and non-visual information in the broader developmental sense.

The TVI relies on the eye doctor's findings to help determine adaptations that are indicated based on a child's diagnosis. Appropriate team recommendations for early intervention services cannot be made without the information derived from the functional vision assessment.

LEARNING MEDIA ASSESSMENT (ESSENTIAL ASSESSMENT)

Learning Media Assessments should be completed by a TVI or an ECTVI and are begun from birth to three years. A learning media assessment is basically an

assessment to determine how the child prefers to learn. The process begins with observation of the infant/toddler's preferred sensory mode (i.e., auditory, visual, tactual) and developing visual skills and over time (prior to leaving the EI/ILP program), the team usually has a fair idea of how to support a child's developing literacy (13).

The following describes prerequisite skills for emergent Braille literacy in infants and toddlers with visual impairment. A similar skill area description exists for emergent print literacy skills for infants and toddlers who will read using large print or other accommodations (14).

- Supporting early literacy development in early childhood settings such as the home and childcare
- Teaching early literacy skills and modeling techniques for fostering development of those skills in the home and childcare, such as reading aloud to the child, developing book concepts, encouraging early reading and writing skills (e.g., pretend reading, scribbling)
- Working with parents and others to expand child's experiential base and general concepts
- Developing hand/finger skills
- Helping parents and others acquire books, labels, and other materials in accessible media
- Helping parents acquire knowledge of Braille and resources for learning the Braille code
- Assuring models of proficient Braille readers; bridging emergent literacy to early formal Braille literacy

ORIENTATION AND MOBILITY EVALUATION (ESSENTIAL ASSESSMENT)

This evaluation is done by an orientation and mobility specialist (OMS). For infants and toddlers, the concept of orientation represents a developmental process of becoming aware of oneself as a separate being, where one is and wants to move in space, and how to get to that place. Mobility refers to general gross motor development, including the normal integration of reflexes, acquisition of motor milestones, refinement of quality-of-movement skills, and purposeful, self-initiated movement. For this age group, orientation and mobility is also a gradual process through which the basic concepts and skills of safe movement develop.

An orientation and mobility evaluation is performed by interviewing the parents, collaborating with the early intervention team members, and directly observing and interacting with the child. In addition to overall developmental information, the OMS is concerned with the child's level of functional vision, hearing, tactile skills, and specific mobility skills. He or she also considers the natural learning opportunities presented to the child within the conditions of the assessment and their possible influence on the child's observed performance (11). The scenario

below describes how an orientation and mobility specialist might work with an early intervention team.

Scenario: An Orientation & Mobility Specialist Helps Facilitate Independent Movement

When evaluated by the physical therapist, Jacob, a 12 month old diagnosed with blindness, demonstrated good static postures in sitting on the floor, standing holding on to furniture, bouncing in his play saucer, and sitting in his highchair. The therapist, concerned because Jacob did not move out into his environment or engage in any dynamic movement at home, requested consultation from an OMS. Together they made a visit to the home, where the OMS observed Jacob's involvement with his mother, therapist, and environment in general. Following this visit, the early intervention team met to discuss what they thought Jacob was ready to do next, motorically.

The OMS explained the following points: Children with severe visual impairments do not learn motor routines incidentally. It is critical that they not be lifted and moved through space to another area if it is possible for them to move on their own or with assistance. Transitional movements (e.g., from floor to standing, from standing to sitting, lying to sitting) are often missed in young children with visual impairments. When caregivers “do for” the child rather than “do with,” the child has no opportunity to learn where he is or how he got from here to there. Jacob needs to be guided through these transitional movements, gradually decreasing assistance until he makes the sequence of movements independently. This is a critical skill for Jacob to obtain before he will move out into his environment on his own. These suggestions were implemented by the family and early intervention specialists in their interactions with Jacob, with the result that he began exploring the environment on his own and learned to move from sitting to standing, standing to sitting, etc.

DEVELOPMENTAL EVALUATION AND ASSESSMENT (ESSENTIAL ASSESSMENT)

The use of standardized measures to determine a young child's present level of functioning does not result in valid scores for the infant or toddler with a visual impairment. However, in collaboration with a TVI or ECTVI, an appropriate criterion referenced tool may be used to gather accurate evaluation and assessment information for the child. Types of criterion referenced tools appropriate for children with visual impairments include The Oregon Project Skills Inventory For Preschool Children Who Are Blind or Visually Impaired, the Brigance IED-II, and the Reynell-Zinkin Scales: Developmental Scales for Young Visually Handicapped.

Developmental evaluation and assessment for infants and toddlers eligible for early intervention services, includes assessing the child in five domains: cognition, physical (including vision, hearing, fine or gross motor), social-emotional, adaptive, and communication/language. Collaboration between the early intervention service provider and the TVI is important throughout the evaluation and assessment process. The TVI can participate in two ways: either as a direct participant by

assessing in his or her particular area of expertise, or as a facilitator or consultant by observing testing to point out when the vision impairment affects the testing items or scoring, and to recommend modifications for the visual impairment.

Knowledge of the unique development of children with visual impairments is critical to accurately interpret assessment results; otherwise, the scores derived may grossly underestimate the child's ability. Parents need to understand how their child's vision impairment affects his development and the results of any developmental evaluation administered to their child.

Scenario: A Teacher of the Visually Impaired Helps a Team Conduct a Developmental Evaluation

Chloe, a 7-month-old diagnosed with optic nerve hypoplasia, was referred for early intervention services. While the family was very interested in getting all the services they might need, they were most interested in understanding their daughter's vision impairment and how it would affect her development. The EI/ILP family service coordinator contacted a TVI to assist with the developmental evaluation process and to help provide support and information for the family. The TVI made several home visits with the therapist and educator during the IFSP team's evaluation of Chloe.

Both the therapist and educator understood that results obtained from any standardized tool used to evaluate Chloe's development would be invalid because of her visual impairment. The TVI helped the team adapt items from a chosen criterion-referenced developmental evaluation tool in order to tease out Chloe's best performance in all areas. With the input of the TVI, the team was able to change Chloe's near environment to allow her to successfully see and act on objects, e.g., increasing contrast by using dark objects with a light yellow background and illuminating the area with appropriate lighting. These adaptations enabled Chloe to demonstrate that she had the ability to reach and grasp objects, activate toys, and locate dropped objects.

Had the visual accommodations not been made, Chloe would not have been able to complete certain test items and her current levels of performance in several areas would have been significantly underestimated. The IFSP team was able to develop meaningful outcomes and help the family learn strategies to help Chloe achieve them.

QUALIFIED SERVICE PROVIDERS

Serving young children with disabilities and their families often involves the collaboration of a number of disciplines. When vision impairment has been diagnosed in an infant or toddler, specialists with expertise in the area of vision impairment may be included on the team. In addition to a TVI or ECTVI, an OMS may be included. Each of these specialists brings a unique perspective for supporting families with children with vision impairments. (Ideally, the TVI will have additional training and experience in working with families and birth to 3-year-olds.)

Early intervention service providers must seek out these services and, at a minimum, establish consulting relationships with TVIs and OMSs in their communities or through state agencies, in order to complete individualized evaluations and assessments. The IFSP must address each child's identified developmental needs and, in this case, the child's need for vision services. Descriptions of specialized service providers for infants and toddlers with visual impairments, both educational/developmental and medical, are provided in Table 1.

Please note that some early intervention service providers have received additional training to better serve young children with vision impairment and families. They are not qualified, however, to provide direct vision services without consultation from a certified TVI or ECTVI to ensure quality services. Those early intervention providers from other disciplines should collaborate with a TVI or ECTVI for evaluations and assessments.

EI/ILP providers will likely work closely with their community or region's eye care specialists, either referring clients for a medical diagnosis, or receiving information from families after a medical diagnosis, and of course, ongoing vision assessments.

Table 1: Descriptions of Specialized Vision Impairment Providers

Teacher of children with visual impairments (TVI or Vision Teacher)	A TVI provides “vision impairment services” to children aged birth to 22 years of age. The training of TVIs is specific to children diagnosed with a vision impairment. TVIs provide early intervention vision impairment services specific to the needs of infants and toddlers, i.e., functional vision assessments, pre-Braille, evaluating the need for adaptive equipment, enhancing development of compensatory skills and instructing all areas of expanded core curriculum.
Early Childhood Teacher of Children with Visual Impairments (ECTVI)	An ECTVI provides “vision impairment services” to children aged birth to 36 months of age. The training of ECTVIs is specific to children diagnosed with a vision impairment and may not provide services to children over 36 months. ECTVIs provide early intervention vision impairment services specific to the needs of infants and toddlers, i.e., functional vision assessments, pre-Braille, evaluating the need for adaptive equipment, enhancing development of compensatory skills, and instructing all areas of the expanded core curriculum.
Orientation and Mobility Specialist (OMS)	An OMS is a professional instructor who teaches a person with a visual impairment how to move safely and efficiently in a variety of environments. This specialist can help the family of an infant or toddler modify the environment and learn strategies to promote movement and safe exploration, for example. In Alaska, most TVIs are also trained and certified orientation and mobility specialists.
Pediatric Ophthalmologist	A pediatric ophthalmologist is a physician specifically trained to diagnose and treat infants and young children with eye diseases. As a medical doctor, he/she is able to prescribe medication and perform surgery when necessary.
Ophthalmologists	An ophthalmologist is a physician specifically trained to diagnose and treat eye diseases. As a medical doctor, he/she is able to prescribe medication and perform surgery when necessary.
Optometrist	Optometrists may screen for common eye problems and prescribe corrective lenses when necessary.
Developmental or Behavioral Optometrist	Developmental optometrists may diagnose and/or prescribe vision therapy intervention for certain eye problems. Vision therapy is a medical, not an educational, intervention service.
Pediatric Optometrist	A pediatric optometrist has specialized training and experience to work with young children with eye problems in need of corrective lenses.
Low Vision Optometrist	These optometrists specialize in evaluating and prescribing special low vision devices for patients with vision impairments.
Optician	Opticians provide the aids (e.g., glasses) prescribed by ophthalmologists and optometrists.

APPROACHES TO INTERVENTION

“Children who are visually impaired are as unique and as varied as any other group of children. One overall statement, however, does apply to most children who are visually impaired: A visually impaired child will typically learn about the world in a different way from a child without a visual impairment.”

—American Foundation for the Blind and National Association for Parents of Children with Visual Impairments

Because vision impairment can affect all areas of development, the family and caregivers must learn ways to enhance the child’s ability to interact with the environment. The desired outcome is that secondary delays will be prevented or minimized.

While best practices dictate that vision services are provided by TVIs, ECTVIs and OMS professionals who have received additional training and who have experience working with infants, toddlers and families, obtaining access to TVI and OMS professionals is difficult in Alaska. Early intervention programs do not routinely have specialists on staff with the expertise to serve these children, and funding consultative services can be difficult (12). Nearly every state is experiencing shortages of TVIs and OMSs.

As a result, delivering quality early intervention services to infants and toddlers with “low incidence disabilities” such as vision impairment can be a challenge. However, children still need to be served, and creative solutions can be found. In order to address the developmental needs of infants and toddlers with visual impairment and their families, we have a responsibility to ensure that qualified personnel deliver services.

PRINCIPLES OF EARLY INTERVENTION

- Qualified professionals conduct ongoing vision evaluation, functional vision assessments, orientation and mobility evaluation, and early intervention.
- Infants and toddlers with vision impairments and their families receive specialized early intervention services integrated into a program that promotes independence for the child within the context of family-centered, community-based activities.
- The IFSP team assists the family in learning about the nature of their child’s vision impairment and its potential impact on their child’s development.

- Early intervention services require a team approach, with the family as an important member of the team.
- Parents and caregivers learn to understand and manage assistive technology and other equipment for their child.
- Parents are knowledgeable about their child’s developmental needs and advocate effectively for their child. Parents understand their rights under the IDEA Part C.(12)

VISION IMPAIRMENT SERVICES

Vision services are one of the 17 early intervention services that an eligible child and family may access under Part C of IDEA. The purpose of this section is to help clarify questions regarding vision services. Infants and toddlers with visual impairment experience differences in all areas of development as a result of their restricted access to the environment and different perceptions of the world. These differences must be considered and addressed as family concerns, priorities and resources are identified as part of developing the IFSP.

Specific components of early intervention should be integrated into IFSPs and services in order to promote optimal development and independence for each child with visual impairments.

A TVI or ECTVI and an OMS help to implement vision services on the IFSP. The TVIs or ECTVIs input guides the family and EI/ILP team in:

- Conducting an initial functional vision assessment
- Evaluating the child’s overall developmental status by adapting assessment tools as appropriate and helping to interpret results
- Developing IFSP outcomes
- Implementing outcomes and services on the IFSP

There is a wide range of individual skills, experience, and areas of specialization among health care professionals and other service providers working in Alaska. Licensed practitioners who work with Alaska’s children should follow the high-quality, evidence-based standards of their professions as determined by their state and national credentialing and professional associations. All providers who work with Alaska's young children should engage only in those aspects of their profession that are within the scope of their competence, considering their level of education, training, and experience.

Direct versus Consultative Services

Infants and toddlers with visual impairment need the services of a TVI, regardless of the severity of the impairment or the presence of additional disabling conditions. In some cases, the TVI or ECTVI may be the primary service provider, while in other cases the TVI or ECTVI will act as consultant to other EI service providers working with a family.

While the following list is not intended to be a “menu of services” for infants and toddlers with visual impairment, the following vision service components should be considered in developing a child’s IFSP.

COMPONENTS OF EARLY INTERVENTION VISION IMPAIRMENT SERVICES FOR INFANTS & TODDLERS

The following vision service components should be considered in developing a child’s IFSP, although it is not intended to be a “menu of services” for infants and toddlers with visual impairment. It has been adapted from the 2003 Policy Statement of the Washington Division of Visual Impairment, Council for Exceptional Children (12).

1. Essential assessments for visually impaired including Functional Visual Assessments, Learning Media Assessments, and Expanded Core Curriculum
2. Development of attachment and meaningful social relationships and communication skills (listening, turn-taking, personal expression, nonverbal communication, emergent literacy).
3. 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
4. Adaptation of environments, toys, and learning materials to make them more accessible
5. 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)
6. Cognitive development opportunities that are experienced-based and designed to teach concepts that are acquired primarily through vision (basic concepts, problem-solving skills)
7. Facilitation of emergent literacy including pre-literacy for potential Braille and print readers through collaboration with families and other professionals
8. 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, print reading and writing if appropriate
9. Development of age-appropriate orientation and mobility instruction (self-directed, independent movement in the environment)
10. Instruction in daily living skills typically acquired through incidental visual learning that must be taught using hands-on, step-by-step procedures to infants and toddlers with visual impairments in order for them to function independently within natural environments (e.g., self-care skills, ability to do household chores)

11. Comprehensive family support that includes emotional support and access to information and resources that will help families become life-long advocates for their children
12. Thorough understanding of medical and visual conditions and their implications for early intervention and education services
13. Recreational opportunities that enhance creativity and enjoyment
14. Instruction in all areas of the expanded core curriculum

The provision of vision services to families of infants and toddlers with visual impairment may take a variety of forms. Frequency and type of vision services will depend on the needs of the child and family as determined by evaluation and assessment and development of the IFSP, as well as the availability of the vision specialists who provide the services. Scarcity of TVIs and/or funding constraints need not be insurmountable barriers. Contact EI/ILP for possible consultation providers.

Direct services. Direct vision services delivered by a TVI, ECTVI or OMS may be required to ensure an appropriate learning environment and support for a child and family— especially when the vision impairment is the “primary” disability. Direct vision services offer the opportunity for hands-on instruction and demonstration, provision of materials and adaptations, provision of initial and ongoing assessment, and instruction of compensatory skills.

Consultative services. The individual needs of the child and family may best be met by consultation to the IFSP team by qualified professionals. Consultation may take the form of periodic in-service training to early intervention practitioners, providing recommendations for appropriate strategies and modifications, and coordinating with related agencies and other resources. Consultative support to the EI team helps ensure that questions are addressed and vision-related recommendations are appropriately implemented. When an EI service provider has participated in advanced training in vision impairment, she is better prepared to work more independently with periodic consultation with a TVI, ECTVI or OMS. However, essential assessments still need to be completed by a TVI, ECTVI or OMS.

ROLE OF VISION IMPAIRED PROFESSIONALS IN EI/ILP

Not all TVIs, ECTVIs and OMS have training or experience with infants and toddlers and families, and they may be uncertain about the nature of their role as consultants to early intervention service providers. The roles summarized below and described in two scenarios in earlier text are intended to help clarify that role for both vision professionals and early intervention service providers (12).

ROLES FOR VISION PROFESSIONALS ON THE IFSP TEAM

Participate in the multidisciplinary evaluation and assessment of infants and toddlers with visual impairment:

- Perform essential assessments
- Perform learning media assessments
- Perform functional vision assessments
- Perform orientation and mobility assessments (by an OMS)
- Instruct the expanded core curriculum
- Obtain and interpret all ophthalmologic, optometric, and functional vision reports for families and other IFSP team members
- Assist with comprehensive developmental evaluation/assessment of infant or toddler, providing input on adaptations of assessment tool items as necessary for visual impairment and assisting with interpretation of results
- Assist with communication skill assessments in pre-reading, listening, picture and tactual communication systems
- Help to address the infant's or toddler's need for assistive technology
- Recommend assessment by other vision specialists as needed (e.g., orientation and mobility)
- Assist families in assessing their concerns, priorities and resources regarding their infant's or toddler's visual development.

Participate in the development of the IFSP:

- Contribute to the infant's or toddler's present levels of performance by discussing how performance is affected by the visual impairment and by providing information on the child's learning style, use of visual information, and other strengths unique to individual infants or toddlers by sharing the results of the essential assessments
- Identify outcomes related to the visual and orientation and mobility needs of the infant or toddler and their family
- Identify frequency, intensity, method, location, and services for meeting IFSP outcomes

Address development of pre-literacy skills and, by age three, recommend appropriate reading and writing media (15)

SAMPLE SCENARIOS: TEACHERS OF THE VISUALLY IMPAIRED ON THE IFSP TEAM

Scenario 1: Helping to Design a Communication System

A speech language pathologist (SLP) on an early intervention team serving Angela, a 2-year-old whose multiple disabilities included cortical visual impairment, wanted to introduce the Picture Exchange Communication System (PECS). Before introducing

Angela and her family to this communication system, the SLP requested input from their county's consulting TVI, who was familiar with Angela's diagnosis and functioning, to ensure appropriate selection of materials.

During the course of several home visits, the SLP and parents discussed with the TVI which pictures/concepts they wished to use to introduce the PECS, the number of pictures from which Angela would make a choice, etc. Based on the results of a functional vision assessment recently completed, the TVI was able to make specific recommendations for the PECS pictures tailored to Angela's visual needs. These included recommendations for: 1) line drawings, which would be easier for Angela to discriminate than photographs; 2) high contrast (e.g., black line drawing of object on yellow background); 3) pictures 3 inches square in size; and 4) presenting pictures on a slant board at a distance of approximately 18 inches.

By sharing expertise, the team did not waste valuable time in a trial-and-error effort to set up a communication system for Angela, and Angela did not experience frustration over a system she was cognitively capable of using but, because of her cortical visual impairment, could not "see."

Scenario 2: Helping to Develop a Feeding Plan

A TVI was asked to consult with an early intervention team to try to determine causes of the feeding problems being experienced by an 18-month-old boy with a diagnosis of blindness. The team consisted of a nurse, a speech and language pathologist, and an occupational therapist, as well as the parents. The little boy was showing resistance to receiving food by spoon and gagged when certain textures of food were presented. Feeding sessions often ended in a general "melt down" of the child and frustration on the part of the parents and therapists.

The TVI observed a feeding session and then the team debriefed. They concluded that there were several issues going on with this child. His medical history, observation, and testing by the therapists suggested that he had an oral sensory problem. The TVI added another dimension, explaining why children who are blind often need to be moved through eating development a little more slowly than other children. She stressed the importance of allowing the child to retain power for himself during feeding, rather than being "acted upon" by the adults. Time and opportunities for exploration needed to be included in the plan as well. After the team discussion, the boy's feeding experiences were restructured and slowed down. He was given more time to finger feed and to explore food textures with his hands before being introduced to spoon feeding. Learning to feed himself took a little longer than for some other children, but was ultimately successful.

MORE INFORMATION

The Texas School for the Blind and Visually Impaired website has more on TVI roles:



www.tsbvi.edu/Education/early-childhood/vi-infant-teacher.htm

PLANNING FOR TRANSITION

As a child approaches 3 years of age, the family's service coordinator and IFSP team, including parents, will work together to plan for a smooth transition from early intervention services to services designed for preschoolers. If the team believes the child will continue to benefit from intervention but may not qualify for special education preschool programs, the service coordinator will help the family locate community-based services and supports.

Whatever their child's particular case, families need to plan for this transition. Starting at the initial IFSP meeting, the service coordinator will talk with the family about what will happen when the child turns three or no longer needs services. At least 6 months prior to the child's third birthday, the team will develop a detailed transition plan that will outline the steps, services, and supports for the child's transition to the appropriate setting. Parents participate in all meetings to ensure a smooth transition for their child.

Transition Planning Tools

EI/ILP Transition Planning Handbook

A detailed, step-by-step guide for parents going through the transition process with a timeline of steps as a child gets older and an overview of the process to create an Individual Education Plan (IEP). Available at:

www.earlyintervention.alaska.gov/afterage3/ilp_StepAhead.pdf

Alaska Transition Training Initiative

A consortium of early childhood programs and providers in Alaska, ATTI helps address transition issues for special needs children moving from Part C to Part B at age 3. Learn more at:

www.alaskaearlytransitions.org/trainers.html

Stone Soup Group: Transitions

Information and resources for parents and caregivers transitioning someone with special needs from one phase of care to the next, including medical and legal issues, guardianship, Medicaid, and transitions into postsecondary programs. Links to parent groups, behavioral supports and assistance programs specifically for kids transitioning from an early intervention to early education can be found at:

www.stonesoupgroup.org/transitions.html

The Paper Trail Notebook

An organizational tool available from the Stone Soup Group, the Paper Trail Notebook can assist the family in identifying and organizing information that will be needed for transition, including records of medical history, appointments and providers. Available at no charge to families of children with special health care needs through EI/ILP providers or directly from the Stone Soup Group at (907) 561-3701 or by visiting:

www.stonesoupgroup.org/papertrail.html

REFERENCES

WORKS CITED

1. Infant Vision, Birth to Twenty-four Months of Life. *American Optometric Association*. [Online] 2011. www.aoa.org/x9420.xml
2. *American Printing House for the Blind*. [Online] www.aph.org/cvi/define.html.
3. Cortical Visual Impairment. *Blind Babies Foundation*. [Online] blindbabies.org/learn/diagnoses-and-strategies/
4. Facts about ROP. *National Institutes of Health, National Eye Institute*. [Online] www.nei.nih.gov/health/rop/rop.asp#7.
5. Retinopathy of Prematurity. *Blind Babies Foundation*. [Online] blindbabies.org/learn/diagnoses-and-strategies.
6. Optic Nerve Hypoplasia. *Blind Babies Foundation*. [Online] 1998. blindbabies.org/learn/diagnoses-and-strategies.
7. **Mark Borchert, M.D., FAAP**. Early detection of optic nerve hypoplasia may improve outcomes. *AAP News*. 2006, 27, pp. 18-19.
8. What is Albinism? *National Organization for Albinism and Hypopigmentation*. [Online] 2007. www.albinism.org/publications/what_is_albinism.html
9. Albinism. *Blind Babies Foundation*. [Online] 1998. blindbabies.org/learn/diagnoses-and-strategies.
10. **American Academy of Pediatrics Committee on Practice and Ambulatory Medicine and Section on Ophthalmology**. Use of Photoscreening for Children's Vision Screening. *Pediatrics*. March 2002, Vol. 109, 3, pp. 524-525.
11. **Pogrund, R. and Fazzi, D., [ed.]**. *Early focus: Working with young children who are blind or visually impaired and their families*. 2nd Ed. NY : AFB Press, 2002. p. 14.
12. *Early Intervention Guidelines for Infants and Toddlers with Visual Impairment in Washington State*. **Hatfield, Nancy and McCutchen, Diane**. s.l. : Washington Sensory Disabilities Services, 2008.
13. Koenig and Holbrook's Learning Media Assessment for Students with Visual Impairments . *Texas School for the Blind*. [Online] www.tsbvi.edu/curriculum-a-publications/3/1037-learning-meadia-assessment-a-resource-guide-for-teachers-2nd-ed.

14. Project SLATE Research. 2003. For further information on this study, contact Cay Holbrook at The University of British Columbia, Scarfe 2311, Faculty of Education, 2125 Main Mall, Vancouver, B.C., CANADA V6T 1Z4, cay.holbrook@ubc.ca, 604-822-2235..
15. **Spungin, S.J. and Ferrell, K.A.** The role and function of the teacher of students with visual handicaps. [ed.] G.S. Erin and J. Pugh. *Blind and visually impaired students: Educational service guidelines (National Association of State Directors of Special Education)*. Watertown : Perkins School for the Blind, 1999.

APPENDICES

1. V.I.S.T.A. Screening Tool
2. Resources

V.I.S.T.A.

Vision Impairment Screening Throughout Alaska
For Early Intervention Programs (0-3)

<input type="checkbox"/> PASS
<input type="checkbox"/> REFER

*MUST BE COMPLETED FOR ALL CHILDREN RECEIVING EI/ILP SERVICES
within 45 days of referral*

Child's Name: _____ Date of Screening: _____

DOB: _____ Screener's Name: _____

If child was previously seen by an eye medical professional you do not need to complete vision screening. Please insert copy of medical report in child's file. If medical report has not arrived by time of evaluation please proceed with vision screening.

Glasses have been prescribed: Yes ___ No ___

A. General History: High Risk Populations for Visual Problems
<p>Is the child diagnosed with one of the following:</p> <p>Cerebral Palsy ___ Congenital (TORCH) Infections ___ Down Syndrome ___ Hearing Loss ___ Head Trauma (TBI) ___ Meningitis ___ Prematurity ___ Substance Abuse/FASD ___</p> <p><i>Visual issues and conditions associated with the above disorders include: Refractive errors, cataracts, CVI, glaucoma, optic nerve hypoplasia (ONH), and strabismus.</i></p>

B. Possible Signs of Visual Impairments	Directly Observed	Parent Report
___ Baby does not react to light or seems excessively sensitive to light		
___ Baby does not gaze or stare at surroundings		
___ Baby does not follow a moving object with eyes		
___ Child holds toy up close to face or is inattentive unless toy has sound cue		
___ Child assumes postures such as head bent down or tilted for visual concentration		
___ Child squints/frowns with fixation, or child stumbles or hesitates to move		
___ Eyes are watery/red/inflamed or eyelids are red/encrusted/watery/swollen		
___ Eyes are visibly out of alignment and do not focus together after 4 months adjusted age		
<i>If any box is checked please refer for outside eye medical exam.</i>		

APPENDIX 1

C. Muscle Imbalance (after 4 months adjusted age)	
<p>Photo Screening: <i>Attach Photo Screener results Label/Certificate</i></p>	<p>Cover Test: (Cover one eye with hand or object) Right Eye: ___ No Movement ___ Movement Left Eye ___ No Movement ___ Movement</p>
	<p>Comments:</p>

Next Steps (Database and Referrals)
<p>If any boxes are checked document in referral out of ILP database. Referral should be to a medical provider (Pediatric Optometrist or Ophthalmologist). If medical report indicates vision is correctable with glasses, surgery, patching etc. monitor according to doctors recommendations. If medical report indicates vision is not correctable, please consult with TVI specialist to assist with intervention strategies and IFSP development. Phone consults are available from TVI to assist with interpreting medical records.</p>

RESOURCES

ALASKA RESOURCES

Alaska Blind Child Discovery (ABCD)

542 West Second Avenue, Anchorage, AK 99501-2242

Toll-free (800) 270-1617. Local (907) 276-1617. Fax (907) 278-1705

Alaska Center for the Blind and Visually Impaired

3903 Taft Drive, Anchorage, AK 99517-3069

Toll-free 1 (800) 770-7517. Local (907) 248-7770

Email info@alaskabvi.org

www.alaskabvi.org

Alaska Early Intervention/Infant Learning Program (EI/ILP) is a division of the Alaska Department of Health and Social Services, Office of Child Services that partners with grantees around the state to provide services directly to children with special needs and their families at a local level.

P.O. Box 240249, 323 East 4th Avenue, Anchorage, AK 99501

Toll-free (877) HSS-FMLY (477-3659). Local (907) 269-8442

Fax (907) 269-3497

www.earlyintervention.alaska.gov

Find a complete list of EI/ILP providers in Alaska at:

www.hss.state.ak.us/ocs/InfantLearning/program/program_dir.htm

Alaska Governor's Council on Disabilities and Special Education (GCDSE) is one of four governor-appointed advisory boards to the Alaska Mental Health Trust. The Council plans, evaluates, and promotes programs for people with disabilities in the state of Alaska.

3601 C Street, Suite 740, P.O. Box 240249, Anchorage, AK 99524-0249

Toll-free (888) 269-8990. Local (907) 269-8990. Fax (907) 269-8995

www.hss.state.ak.us/gcdse

Alaska Independent Blind

1561 Nelchima St - Unit C-1, Anchorage, AK 99501-5577

Toll-free (800) 478-9998. Local (907) 563-2525. Fax (907) 276-0066

Email aiblink@ak.net

www.acb.org/alaska

APPENDIX 2

Alaska Lions Clubs has been a leader in providing exams and recycling eye glasses in the state. Contact the Lions Club at (907) 566-1597 to apply for Lions Club assistance. To contact the Lions Club eyeglass recycling and vision center contact:

Aurora Borealis Lions Eyeglass Recycling and Vision Center
2925 Newby Road, P.O. Box 55933, North Pole, AK 99705
Local (907)378-7797. Fax (907) 488-6164 | Email hdcrixie@alaska.net

Alaska Optometric Association

1501 W 36th Ave, Ste. 230, Anchorage, AK 99503
Toll-free (877) 693-2562. Local (907) 770-3777. Fax (907) 272-7532
Email akoa@alaska.com

Alpine Alternatives, Inc.

2518 East Tudor Road, Suite 105, Anchorage, AK 99507
Toll-free (800) 361-4174 | (907) 561-6655. Fax (907) 563-9232
Email info@alpinealternatives.org
www.alpinealternatives.org/programs.html

Assistive Technology of Alaska (ATLA). As the state's Tech Act Project, ATLA provides Alaska's most comprehensive assistive technology resources, including assessments, training, webinars, demonstrations, education and AT device loans, including technology for deaf and hard of hearing.

3330 Arctic Blvd., Ste.101, Anchorage, AK 99503
Toll-free (800) 723-2852(ATLA). Local (907) 563-2599. TTY (907) 561-2592.
Fax (907) 563-0699 | Email atla@atlaak.org
www.atlaak.org

NATIONAL AND ONLINE RESOURCES

American Foundation for the Blind (AFB)

2 Penn Plaza, Suite 1102, New York, NY 10121
Toll-free (800) AFB-LINE (232-5463). Fax (888) 545-8331
Email afbinfo@afb.net
www.afb.org

American Printing House for the Blind

1839 Frankfort Avenue, P.O. Box 6085, Louisville, KY 40206-0085
Toll-free (800) 223-1839. Fax (502) 899-2284
Email info@aph.org
www.aph.org

National Association of Parents of the Visually Impaired (NAPVI)

P.O. Box 317, Watertown, MA 02471
Toll-free (800) 562-6265. Fax (617) 972-7444
Email napvi@perkins.org
www.napvi.org

National Federation of the Blind

200 East Wells Street at Jernigan Place, Baltimore, MD 21230
Phone (410) 659-9314. Fax (410) 685-5653
www.nfb.org

National Organization of Parents of Blind Children

c/o National Federation of the Blind
200 East Wells Street at Jernigan Place, Baltimore, MD 21230
Phone (410) 659-9314. Fax (410) 685-5653
www.nfb.org/nfb/parents_and_teachers.asp

Additional Copies or Services

*These guidelines are available online at www.earlyintervention.alaska.gov
To request additional copies or auxiliary aids and services, please contact:*

Alaska Early Intervention/Infant Learning Program
P.O. Box 240249
323 East 4th Avenue
Anchorage, Alaska 99501

Toll-free (877) HSS-FMLY (477-3659)
Local (907) 269-8442
TT Relay (800) 770-TYPE (8973)



Alaska Infant Learning Program

This report, historical data and other publications available at www.earlyintervention.alaska.gov

Call toll free in Alaska: 1 (877) HSS-FMLY (477-3659); In Anchorage 269-8442

INFANT LEARNING PROGRAMS THROUGHOUT ALASKA



The Alaska Infant Learning Program offers developmental services to families of children birth to 3. If you have concerns about your child's development make a referral to your local Infant Learning Program. Our Mission is to promote positive development and improved outcomes for Alaska's children birth to 3 by creating a culturally responsive, comprehensive and accessible service delivery system that links service providers, empowers families and engages communities.