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Assessment and Intervention
for Young Children
(Age 0-3 Years)

CLINICAL PRACTICE GUIDELINE

QUICK REFERENCE GUIDE
FOR PARENTS AND PROFESSIONALS

VISION IMPAIRMENT
ASSESSMENT AND INTERVENTION
FOR
YOUNG CHILDREN (AGE 0-3 YEARS)

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3. *Clinical Practice Guideline*: *Quick Reference Guide*.
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Vision Impairment

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Foreword

Providing an optimal program of early intervention for young children with developmental disabilities and their families requires knowledge of the most current information on research and practice. However, analyzing research studies and determining their relevance to practice can be a perplexing task even for the professional. This is especially the case for low incidence disabilities such as children with vision impairments where the often limited available evidence requires an unusual level of care and thoughtfulness to discern patterns that can inform practice.

Despite the fact that this is a difficult task, practice guidelines based on a sophisticated and rigorous analysis of the extant research literature can convey essential information for the design, implementation, and evaluation of optimal early intervention programs. By combining this information with an understanding of the developmental patterns of children with vision impairments, an especially powerful analysis can result. *The Clinical Practice Guideline for Vision Impairment* has been the result of such a sophisticated and methodologically sound approach to accurately gather and summarize information based on the available evidence. This Guideline is of extraordinary value to practitioners from all relevant disciplines, and to parents, administrators, and others interested in the health and well-being of young children with vision impairments.

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PREFACE

WHY THE BUREAU OF EARLY INTERVENTION IS DEVELOPING GUIDELINES

In 1996, a multiyear effort was initiated by the New York State Department of Health (NYSDOH) to develop clinical practice guidelines to support the efforts of the statewide Early Intervention Program. As lead agency for the Early Intervention Program in New York State, the NYSDOH is committed to ensuring that the Early Intervention Program provides consistent, high-quality, cost-effective, and appropriate services that result in measurable outcomes for eligible children and their families.

This guideline is a tool to help assure that infants and young children with disabilities receive early intervention services consistent with their individual needs, resources, priorities, and the concerns of their families.

The guideline is intended to help families, service providers, and public officials by offering recommendations based on scientific evidence and expert clinical opinion on effective practices for the following:

- Early identification of children who are either at risk for or suspected of having a disability, through routine developmental surveillance and screening targeted to identify specific disabilities.

- Provision of multidisciplinary evaluations and assessments that result in reliable information about a child's developmental strengths and needs and, when possible, a diagnosis.

- The determination of effective intervention strategies and reaching agreement on the frequency, intensity, and duration of early intervention services that will lead to positive outcomes for children and families.

- The measurement of outcomes achieved.

The impact of clinical practice guidelines for the Early Intervention Program will depend on their credibility with families, service providers, and public officials. To ensure a credible product, an evidence-based, multidisciplinary panel consensus approach was used. The methodology used for these guidelines was established by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Healthcare Policy and Research (AHCPR). The NYSDOH selected the AHCPR model for this effort because it is an effective, scientific, and well-tested approach to guideline development.

The NYSDOH has worked closely with the State Early Intervention Coordinating Council throughout the guideline development process. A state-level steering committee of early intervention officials, representatives of service providers, and parents was also established to advise the NYSDOH on this initiative. A national advisory group of experts in early intervention has been available to the NYSDOH to review and provide feedback on the methodology and the guideline. Their efforts have been crucial to the successful development of this guideline.

Overview of the Early Intervention Program

The New York State Early Intervention Program is part of the national Early Intervention Program for infants and toddlers with disabilities and their families, first created by Congress in 1986 under the Individuals with Disabilities Education Act (IDEA). IDEA is the federal law that ensures all children and youth ages 3 to 21 years with disabilities the right to a free appropriate public education. In New York State, the Early Intervention Program is established in Article 25 of the Public Health Law and has been in effect since July 1, 1993.

To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and adaptive development.

The Early Intervention Program offers a variety of therapeutic and support services to infants and toddlers with disabilities and their families, including family education and counseling, home visits, and parent support groups; special instruction; speech pathology and audiology; occupational therapy; physical therapy; psychological services; service coordination; nursing services; nutrition services; social work services; vision services; and assistive technology devices and services.

Major provisions of the New York State Public Health Law that govern the Early Intervention Program require:

▪ Local administration of the program by an Early Intervention Official (EIO) designated by the chief elected official of each of the fifty-seven counties and New York City. The EIO is responsible for ensuring that eligible children and their families receive the services included in the Individualized Family Service Plan (IFSP) that is developed for the child and family.

- Identification and referral of children who are either at risk for or suspected of having a disability by primary referral sources (including physicians and other health care providers).

- Periodic developmental screening and tracking of at-risk children.

- Provision of service coordination services to eligible children and their families.

- A multidisciplinary evaluation of children referred to the program, at no cost to the family, to determine eligibility.

- Development of an IFSP for eligible children and their families.

- Provision of early intervention services, as specified in the IFSP, at no cost to the family.

- Delivery of services in natural settings in the community where peers are typically found, to the maximum extent appropriate.

The mission of the Early Intervention Program is to identify and evaluate as early as possible infants and toddlers whose healthy development is compromised, and provide for appropriate interventions to improve child and family development. The program goals are to:

- Support parents in meeting their responsibilities to nurture and to enhance their children's development.

- Create opportunities for full participation of children with disabilities and their families in their communities by ensuring services are delivered in natural environments to the maximum extent appropriate.

- Ensure early intervention services are coordinated with the full array of early childhood health and mental health, educational, social, and other community-based services provided to children and their families.

- Enhance child development and functional outcomes and improve family life through delivery of effective, outcome-based, high-quality early intervention services.

- Ensure that early intervention services complement the child's medical home by involving primary and specialty health care providers in supporting family participation in early intervention services.

- Assure equity of access, quality, consistency, and accountability in the service system by ensuring clear lines of public supervision, responsibility, and authority for the provision of early intervention services to eligible children and their families.

New York State Public Health Law designates the NYSDOH as the lead agency for this statewide program. As the lead agency, the NYSDOH is responsible for the overall supervision and administration of the Early Intervention Program. Responsibilities include:

- Implementing statewide policies, procedures, and programmatic and reimbursement regulations.

- Implementing a comprehensive public awareness and child find system.

- Approving, compiling, and disseminating lists of approved service coordinators, evaluators, and service providers.

- Providing training and technical assistance to municipal and service providers to enable them to identify, locate, and evaluate eligible children; developing IFSPs; ensuring the appropriate provision of early intervention services; and promoting the development of new services where there is a demonstrated need.

- Safeguarding parent and child rights under the Early Intervention Program.

- Establishing and maintaining an Early Intervention Coordinating Council to advise and assist the department in program implementation.

Early Intervention Policy ❖ Throughout the document, information about relevant Early Intervention Program policy is presented in boxes with this symbol.

GLOSSARY OF COMMON TERMS RELATED TO VISION AND VISION IMPAIRMENT

Amblyopia – a visual defect that affects visual acuity (clarity) due to poor muscle control in one eye. It is noted by reduced vision not correctable by glasses or contact lenses and is not due to any eye disease. Amblyopia (sometimes referred to as "lazy eye") is often confused with strabismus (crossed eyes; eyes that wander, turn, or deviate).

Anisometropia – a condition in which each eye has a different refractive error. For example, one eye is mildly myopic (nearsighted), while the other is very myopic.

Binocular – of or involving both eyes at once.

Binocular Vision – the ability to use both eyes together at the same time.

Esotropia – a muscle condition in which one eye is turned inwards when both eyes are open.

Exotropia – a muscle condition in which one eye is turned outwards when both eyes are open.

Myopia – nearsighted; distant objects appear blurred because their images are focused in front of the retina rather than on it.

Hyperopia – farsighted; vision is better for distant than near objects because images are focused behind the retina rather than on it.

Orthoptic Therapy – a limited form of vision therapy.

Pursuit – eye movement for fixating and following a (continuously) moving target.

Saccade – jumping eye movement for changing fixation from one stationary target to another.

Stereopsis – (stereopsis or stereoscopic vision) a byproduct of good binocular vision; vision wherein the separate images from two eyes are successfully combined into one three-dimensional image in the brain.

Strabismus – strabismus may be called eye turns, crossed eyes, cross-eyed, wall-eyes, wandering eyes, deviating eye, etc. Strabismus is not the same condition as amblyopia. Strabismus is defined as a condition in which the eyes deviate (turn) when looking at an object.

Vision Therapy (also known as vision training, visual therapy, visual training) – therapy involving procedures (eye exercises) aimed at improving visual skills.

Visual Acuity: Distance – clarity of sight (sharpness, clearness) at 20 feet distance.

Visual Acuity: Near – clarity of sight for short distance (specifically, reading distance).

LIST OF COMMON ABBREVIATIONS

AT	Assistive technology
CAT/CT	Computerized Axial Tomography
CP	Cerebral Palsy
CPD	Cycles per degree
CVI	Cortical visual impairment
EIO	Early Intervention Official
EIP	Early Intervention Program
ERG	Electroretinogram
HOTV	Tumbling E visual acuity eye chart
IDEA	Individuals with Disabilities Education Act
IFSP	Individualized Family Service Plan
IOL	Intraocular lenses
MRI	Magnetic Resonance Imaging
NICU	Neonatal intensive care unit
NLP	No light perception
NYSDOH	New York State Department of Health
O&M	Orientation and Mobility
OD	Doctor of Optometry
OKN	Optokinetic nystagmus
PVL	Periventricular leukomalacia
RDE	Random Dot E Stereotest
ROP	Retinopathy of prematurity
RP	Retinitis pigmentosa
RT	Rehabilitation teaching specialists
TAC	Teller acuity cards
TVI	Teacher of the visually impaired
VEP	Visual evoked potential
VER	Visual evoked response
VLBW	Very low birth weight

CLINICAL PRACTICE GUIDELINE

QUICK REFERENCE GUIDE
FOR PARENTS AND PROFESSIONALS

VISION IMPAIRMENT
ASSESSMENT AND INTERVENTION
FOR
YOUNG CHILDREN (AGE 0-3 YEARS)

This *Quick Reference Guide* is an abbreviated version of the background information and guideline recommendations presented in the full text reports of this clinical practice guideline.

The full text of all the recommendations, plus a description of the methodology and evidence used to develop the recommendations, can be found in *Clinical Practice Guideline: The Guideline Technical Report*.

The full text of all the recommendations, plus an abbreviated description of the methodology and evidence used to develop the recommendations, can be found in *Clinical Practice Guideline: Report of the Recommendations*.

CHAPTER I: INTRODUCTION

PURPOSE OF CLINICAL PRACTICE GUIDELINES

This *Quick Reference Guide* is based on *Clinical Practice Guideline Technical Report* that was developed by an independent, multidisciplinary panel of clinicians and parents sponsored by the New York State Department of Health. The development of this and other guidelines for the statewide Early Intervention Program was sponsored by the New York State Department of Health as part of its mission to improve the quality of care for children with disabilities.

This clinical practice guideline on vision impairment is intended to provide parents, professionals, and others with recommendations about "best practice" based on consensus opinion of the panel and scientific evidence about the efficacy of various assessment and intervention options for young children who are visually impaired.

The primary reasons for developing a clinical practice guideline for young children with vision impairment are to:

- Help children and their families learn about appropriate and effective services
- Provide an education and information resource for professionals
- Promote consistency of service delivery
- Facilitate productive communication among professionals
- Facilitate quality improvement in early intervention services
- Indicate where more research is needed

> *Note: The guideline is not a required standard of practice for the Early Intervention Program administered by the State of New York. The guideline document is a tool to help providers and families make informed decisions.*
>
> *Providers and families are encouraged to use this guideline, recognizing that the care provided should always be tailored to the individual. The decision to follow any particular recommendations should be made by the provider and the family, based on the circumstances of the individual children and their families.*

SCOPE OF THIS GUIDELINE

This clinical practice guideline provides recommendations about best practices for assessment and intervention methods for children with vision impairment. The primary topics addressed in this guideline are:

- **Vision impairments in children younger than three years of age**

  The primary focus of the guideline is children from birth to three years old. However, age three is not an absolute cutoff. Many of the recommendations may be applicable to somewhat older children.

- **Vision impairments that are not correctable to at least the moderate low vision level**

While there are many types of vision impairment, it is generally the level of severity of the vision impairment (Table 4, page 13) that determines the extent of functional impact on the individual. For this guideline, the primary focus of the recommendations is children with visual impairments that are not correctable to at least the moderate low vision, regardless of etiology.

While moderate low vision is generally defined in terms of visual acuity (see page 9), defining visual impairment in terms of visual acuity for infants and young children may not be strictly applicable because visual acuity develops over time, and development of the visual system continues until children are approximately 6 years old. Furthermore, individuals with the same visual acuities may function in different ways.

Some less severe vision impairments also are discussed in a limited fashion in the guideline. For example, amblyopia may not cause significant early problems with vision or disabilities that would qualify a child for the Early Intervention Program. However, a brief discussion of amblyopia is included because if it is not identified and corrected during childhood, reduced vision could result and eventually lead to permanent visual impairment in the affected eye.

Early Intervention Policy ❖ Children with a diagnosed vision impairment, including blindness, low vision, optic nerve coloboma, grades 4 and 5 retinopathy of prematurity, albinism, aniridia, and visual deprivation nystagmus, are eligible for the Early Intervention Program because of their having a diagnosed condition with a high probability of a developmental delay.

HOW THE GUIDELINE WAS DEVELOPED

A multidisciplinary panel of topic experts, general providers (both clinicians and educators), and parents worked together to develop the guideline. After determining the guideline's general scope, the guideline panel established the specific assessment and intervention topics and decided which topics were most appropriate for the evidence review process. The panel then held a series of meetings to review the available research and develop recommendations. The panel's final meeting was in 2001.

For some topics, no research evidence meeting the criteria of the guideline was found. Other topics were determined to be inappropriate for a literature search and evidence evaluation. Upon panel review of these topics, recommendations were developed through member consensus.

Using Scientific Evidence to Develop Guidelines

Every professional discipline today is being called upon to document the effectiveness of specific approaches in bringing about desired outcomes. Guidelines based on an evaluation of the scientific literature can help professionals, parents, and others learn what scientific evidence exists about the effectiveness of specific clinical methods. When adequate scientific evidence can be found and systematically evaluated, it provides a balanced and objective approach for making informed decisions.

This version of the guideline provides only a summary of the guideline recommendations. Detailed information about the research process is described in the more complete versions of the guideline.

DEFINITIONS OF COMMON TERMS

Assessment   The entire process of identifying and evaluating the child, including the activities and tools used to measure level of functioning, establish eligibility for services, determine a diagnosis, plan intervention, and measure treatment outcomes.

Family   The child's primary caregivers, who might include one or both parents, siblings, grandparents, foster care parents, or others usually in the child's home environment(s).

Parent(s)   The child's primary caregiver. The primary caregivers are those who have significant responsibility for the welfare of the child. The primary caregiver may be someone other than the mother or father of the child.

Professional   Any provider of a professional service who is qualified by training, experience, licensure, and/or other state requirements to provide the intended service. The term is not intended to imply any specific professional degree or qualifications other than appropriate training and credentials. It is beyond the scope of this guideline to address professional practice issues.

Screening   The early stages of the assessment process. Screening may include parent interviews or questionnaires, observation of the child, or use of specific screening tests. Screening is used to identify children who need more in-depth assessment.

Target Population   Children from birth to age 3 years with visual impairment. Throughout this document, the term *young children* is used to describe this age group.

Vision Impairment   Vision (or visual) impairment generally refers to any visual impairment that is not correctable to better than moderate low vision, regardless of etiology.

Young Children   Used broadly to describe the age group that is the focus of this guideline (children from birth to age 3 years).

Early Intervention Policy ❖ The terms *assessment*, *parents*, and *screening* are defined in regulations that apply to the Early Intervention Program in New York State. (See Appendix B, "Early Intervention Program Information.")

In New York State, the term used for professionals who are qualified to deliver early intervention services is *qualified personnel*. Qualified personnel are those individuals approved to deliver services to eligible children, to the extent authorized by their licensure, certification, or registration, and who have appropriate licensure, certification, or registration in the area that they are providing services (see Appendix B).

The "Glossary of Common Terms Related to Vision and Vision Impairment" is on page xix, and the "List of Common Abbreviations" is on page xxi in the front of this book.

CHAPTER II: BACKGROUND INFORMATION

WHAT IS VISION? HOW DOES THE EYE WORK?

Vision occurs when the eye receives images and transmits them to the brain. Vision is a complex process that involves the eye, the brain, and the pathways between them. The eye has a system similar to a video camera connected to a computer that controls the amount of light allowed in and then focuses light rays onto the back of the eye to be transmitted to the brain. This system includes the eyelids, the cornea (a clear layer that covers the front of the eye), the iris (the circle of color around the pupil), the pupil (the black center of the eye that controls the amount of light), and a lens (the part of the eye that focuses the image).

Figure I: Structure of the Eye

Structure of the Eye
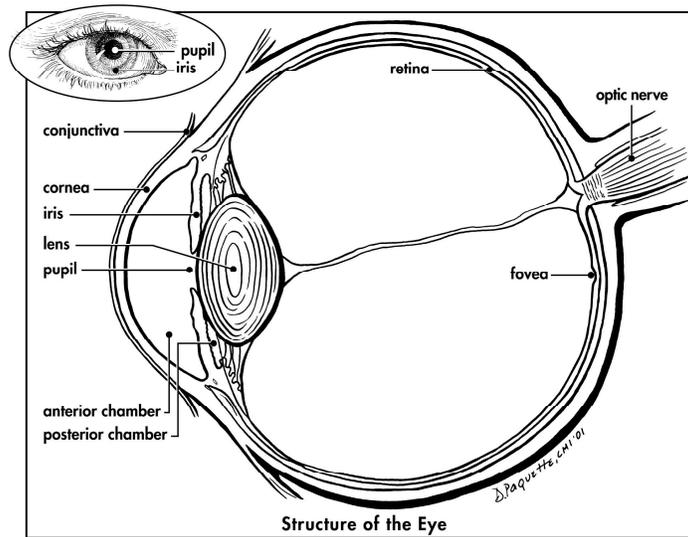
Another important part of the eye is the retina. The retina is at the back of the eye, and it contains different types of light-sensing nerve cells generally classified as *photoreceptors*:

- Cones are the receptors for daylight vision and respond to colors, movement, and high- and low-contrast forms

- Rod cells are the receptors for night vision and 'see' everything as shades of gray

The photoreceptors in the retina convert the light into "nerve impulses" that travel through the optic nerve to the brain. The brain then interprets these nerve impulses and produces an image. Not only is an image produced, but also information is received about important characteristics of the image, such as its placement, motion, and localization in space. This information allows a person to fixate on an object and identify it. There are over 30 areas in the brain that are involved in receiving and translating visual information.

Development of the visual system

Babies are born with the ability to see, but their visual system is not fully developed at birth. As the visual system matures over the first few years of life, vision improves, and the child's ability to interpret and understand the visual images develops.

The immaturity of the visual system in infants and young children allows for flexibility and responsiveness to changes in visual stimulation. This is referred to as plasticity. After the visual system has completely matured (thought to be when children reach approximately 10-12 years of age), plasticity is significantly reduced.

WHAT IS NORMAL VISION?

When describing vision, most people tend to think of good (or "normal") vision as the ability to see clearly at all distances without glasses. This is commonly referred to as "20/20" vision. The expression "20/20" is a description of *visual acuity* (the ability to discriminate detail) based on how clearly images such as letters, numbers, or pictures are seen on the Snellen eye chart, the most common measure of visual acuity. The Snellen visual acuity rating is written as a fraction:

- The top number is the testing distance

- The bottom number is the distance at which a person with normal visual acuity would be able to read the letter

For example, a person with 20/20 vision sees at 20 feet what a person with normal visual acuity sees at 20 feet. A person with 20/200 vision can see clearly at 20 feet what a person with normal visual acuity is able to see at 200 feet.

Sometimes, instead of a fraction, the decimal equivalent is used to report visual acuity results. In this method, normal visual acuity would be reported as 1.00.

The Snellen acuity test measures distance vision. Table 1 shows examples of equivalent measurements for close vision.

Table 1: Approximate Near-Vision Visual Acuity Equivalents

Snellen	Near-Vision Equivalents						
Distance Vision	**Meters Equiv.**	**Jaeger**	**AMA Notation**	**Point Size**	**Approx. Height**	**Visual Angle**	**Text Size**
20/20	0.4 M	—	14/14	3	.58 mm	5.00	—
20/25	0.5 M	J1	14/17.5	4	.75 mm	6.25	footnotes
20/40	0.8 M	J4	14/28	6	1.15mm	10.00	paperback book
20/50	1.0 M	J6	14/35	8	1.50mm	12.50	newspaper print
20/60	1.2 M	J7	14/42	9	1.75mm	15.00	magazine print
20/80	1.6 M	J9	14/56	12	2.30mm	20.00	children's book
20/100	2.0 M	J11	14/70	14	3.00mm	25.00	large print book
20/200	4.0 M	J17	14/140	20	6.00mm	50.00	small headlines
20/250	5.0 M	J18	14/175	—	7.50mm	62.50	large headlines
20/500	10.0 M	J19	14/350	—	15.00mm	125.00	½-inch letter
20/1000	20.0 M	J21	14/700	—	30.00mm	250.00	1-inch letter

Note: Snellen measures distance vision. The other measurement values indicate the near-vision equivalents.

Development of normal visual acuity

Good visual acuity requires proper functioning of both the eye and the neural components of the visual system. For the visual pathways to develop properly, the brain needs to receive equally clear, focused images from both eyes at the same time.

At birth, the visual acuity of the immature visual system is less than 20/200, but this usually improves to 20/20 within the first three years. Normal visual acuity has been estimated to be approximately 20/400 in the full-term baby. Although the norms for tests of visual acuity may be somewhat different from test to test, there is general agreement that normal visual acuity improves over at least the first three years of life (Table 2).

Table 2: Development of Normal Visual Acuity

Cardiff Acuity Test

Age Interval (Months)	Snellen Equivalent	
	Using Both Eyes	**Using Only One Eye**
12 – 18	20/160 to 20/40	20/127 to 20/50
18 – 24	20/80 to 20/25	20/100 to 20/25
24 – 30	20/50 to 20/25	20/63 to 20/25
30 – 36	20/40 to 20/20	20/40 to 20/20

Adapted from: Adoh 1994

Other visual functions

In addition to visual acuity, vision also includes many other functions such as visual field, color perception, contrast sensitivity, sensitivity to light/glare, dark adaptation, depth perception, and binocularity (Table 3, page 12).

Table 3: Visual Functions

Vision incorporates three basic functions: form perception, light perception, and motion perception.

Term	Definition
Visual acuity	The ability to discriminate fine details; reduced visual acuity results in objects having less resolution (less detail)
Visual field	The area within which objects may be seen when the eye's position is fixed; peripheral vision; visual field may be changed in many ways. For example, significant loss of peripheral vision can be like looking through a small tube (tunnel vision)
Color perception	The ability to see and distinguish colors (the main three color factors are red, green, and blue); reduced color perception causes confusion between certain shades of color
Contrast sensitivity	The ability to discriminate between lightness and darkness; reduced contrast sensitivity makes things look washed out or faded
Dark adaptation	The adjustment of the eyes for vision in dim light
Binocularity	Using both eyes together to create a single image and depth perception
Ocular motility	How the eyes move when a person follows an object into the various positions of gaze
Accommodation	The ability to shift focus from near to far and far to near

WHAT IS VISION IMPAIRMENT?

Vision impairment is the loss of some aspect of vision that reduces a child's ability to see. Vision impairments range in severity from mild vision loss to total absence of light perception. This guideline focuses on vision impairments that are severe enough to interfere with a young child's information processing and learning through the sense of vision.

Although many children need glasses in order to see clearly, uncorrectable vision impairments are among the least prevalent disabilities in children. Approximately 1 in every 3,000 infants is born with a severe vision impairment. However, because vision is the perceptual system that is most suited for gaining information about the environment, particularly information about shape and

space, and is an integral aspect of a child's early learning process, vision impairments can have a significant adverse effect on multiple aspects of a child's development.

Table 4: Levels of Severity of Vision Impairments

Level of Severity	Best Correctable Snellen Acuity Equivalent[1]
Normal vision	20/25 or better
Near normal vision	20/30 to 20/60
Moderate low vision	20/70 to 20/160
Severe low vision	20/200 to 20/400
Profound low vision	20/500 to 20/1000
Near total blindness	less than 20/1000
Total blindness	No light perception (NLP)

[1]*Note: These definitions apply to adult levels of visual acuity.*
Adapted from: ICD-9 Manual 1998

Visual acuity in the moderate, severe, and profound impairment categories are sometimes referred to as "low vision," whereas in general, best correctable visual acuity of less than 20/500 may be referred to as "blindness." However, definitions of blindness may vary in different settings.

Sometimes, vision professionals may refer to "legal blindness," which is defined as a visual acuity of 20/200 (or the metric equivalent of 6/60) or less in the better eye after the best possible correction has been given. The legal definition of blindness was created primarily for adults in order to determine eligibility for government assistance and rehabilitation. Many individuals who are legally blind have enough sight that they can read print at close range and use their vision for mobility purposes. A person can sometimes be classified as "legally blind" because of visual field restrictions. However, visual field can be difficult to measure in young children and therefore is rarely used in classifying vision impairment in children from birth to 3 years of age. Poor visual acuity is the most common reason for blindness in young children.

Visual function

Professionals working with young children having vision impairment are usually more interested in a child's visual function (the amount of useful vision an individual has) rather than the visual acuity per se. Two broad levels of visual function may be sufficient to describe developmentally different populations of children who have vision impairments. These populations are:

▪ Children whose best correctable visual acuity ranges from 20/70 to 20/500: these children are able to perform visual tasks although perhaps not as efficiently as normally sighted children.

▪ Children whose best correctable visual acuity ranges from 20/800 to no light perception: for these children, available vision is unreliable and only sufficient for gross visual tasks.

A cutoff somewhere between 20/500 and 20/800 separates these two populations. Children whose best correctable visual acuity of 20/500 or better may have enough functional vision to see and interact with the objects and people around them, to move around and explore, and to imitate actions. Children whose best correctable visual acuity is 20/800 or less may not have enough functional vision.

WHAT CAUSES VISION IMPAIRMENT?

Visual impairment can be the result of a problem either in the eye itself or in the visual nervous system. A child's diminished ability to see may be related to a problem with any one or more of the following:

▪ Allowing the light to pass through the eye
▪ Focusing the light appropriately on the retina
▪ Causing a reaction to occur within the photoreceptors of the retina
▪ Transmitting the information via the optic nerve and visual pathways
▪ Receiving/interpreting visual information by the brain
▪ Integrating the information and providing appropriate feedback to the eye and extraocular muscles so that fixation can be maintained on the target

Worldwide, the most common cause of vision impairment is ulceration of the cornea, secondary to vitamin A deficiency. In the United States, the most common disorders of the visual system include cortical visual impairments (CVI), retinopathy of prematurity (ROP), optic nerve hypoplasia, and structural abnormalities.

These different eye conditions are generally associated with different levels of visual function, and some also may be associated with more general central nervous system damage that can result in simultaneous disabilities such as mental retardation or cerebral palsy. Table 5 lists some of the eye conditions that can result in vision impairments.

Table 5: Ocular and Visual Disorders (Eye Conditions)

Many of these conditions are congenital (present at birth), and some are surgically or medically treatable.

- *Albinism* – a group of genetic conditions characterized by hypopigmentation of the eyes, resulting in nystagmus, photophobia, and reduced visual acuity
- *Cataract* – opacity (a cloudiness) of the eye lens or its capsule, or both
- *Cortical visual impairment (CVI)* – reduced vision due to cortical damage in one or more areas of the brain; frequently associated with other neurological impairments
- *Glaucoma* – increased pressure in the eye (intraocular pressure) causing damage to the optic nerve and other structures in the eye
- *Optic nerve dysplasia* – the optic nerve develops abnormally during fetal development
- *Optic nerve hypoplasia* – the optic nerve is small because it does not develop completely during fetal development
- *Retinoblastoma* – a malignant tumor of the retina
- *Retinopathy of prematurity (ROP)* – a bilateral disease of the retinal vessels present in premature infants (formerly called retrolental fibroplasia); scarring of the retina caused by the growth of blood vessels into the retina; in some extreme cases, leads to retinal detachment and total blindness

The following are less serious disorders with later onset of visual dysfunction that lead to reduced visual acuity if they are not recognized and treated in time:

- *Amblyopia* – the decrease in visual acuity, almost always unilateral, that occurs in visually immature children due to lack of a clear image falling on the retina
- *Nystagmus* – involuntary, cyclical movement of the eyeball; may be hereditary or secondary to another ocular or neurologic problem
- *Strabismus* – ocular misalignment, squint

Adapted from: Lennerstrand 1995

While there has been an increase in childhood visual impairment attributable to genetic causes in the past 50 years, this increase does not represent an absolute increase in the prevalence of inherited disorders that cause blindness. The increase is due in part to the decrease in infectious diseases that can result in childhood visual impairment, especially rubella (German measles). Maternal rubella infection is associated with a high rate of congenital cataracts.

WHAT IS THE IMPACT OF VISION IMPAIRMENT ON DEVELOPMENT?

Vision impairment during infancy and early childhood can adversely affect multiple aspects of a child's development. Vision is the perceptual system that is most suited for gaining information about the environment, particularly information about shape and space. Vision also is an important factor in early interactions between the infant and the parent(s). It is not surprising that children who have reduced sensory information because of vision impairment often find it more difficult to acquire various developmental skills and therefore demonstrate delays in development. Some children with vision impairment show not only delays but also different patterns of development when compared with typically developing children.

Overall development

The overall developmental consequences of vision impairment depend on both children's visual function and any simultaneous global developmental delays. Children with visual function of 20/800 or less show lower developmental age scores across time on the Battelle Developmental Inventory (BDI) for all of the developmental domains when compared to the development of children with better vision.

Motor development

Of all the developmental domains, the motor domain may be the most adversely affected by severely impaired visual function. Children who are severely visually impaired (even those without other impairments) tend to be delayed in all areas of motor development when compared with the same standard milestone tables as children who are sighted.

In normally sighted children, early motor development and cognitive development are closely related. To be motivated to reach for people or objects and to move, a child has to have enough vision to see that something is present. If a child does not have enough functional vision, the child will have to learn to

reach and move by localizing the sound. Realizing that something is present in the environment based on auditory cues is a cognitive skill that generally develops later than visually directed reaching does.

Visual information provides not only sensory stimulation to motivate movement but also feedback that facilitates continuous correction of movement. Therefore, the quality of movement may be different in children who have a vision impairment.

Cognitive development

Cognitive development also is delayed in children who have severely impaired visual function, compared with children who have better vision. Early cognitive development and motor development are interrelated and can affect a child's ability to interact with objects and people.

In particular, object concept (understanding the relatedness of objects to other objects, events, persons, and experiences) and object permanence (understanding that something still exists even when it is not present) tend to be delayed in young children who are blind. Blind children's delays in obtaining the object concept can then result in delays in understanding other concepts, particularly those relating to spatial relationships and the relationship between cause and effect.

Communication and social/emotional development

Vision impairment may adversely affect some aspects of a child's communication development, but communication development may be impacted less than the development in other domains. Many children with vision impairment acquire language within the same range as normally sighted children do.

However, much of communication involves nonverbal cues, which are primarily visual and which are an important aspect of social interaction. Social interaction scores on the Battelle Developmental Inventory are lower for children who have severely impaired visual function compared with children who have better vision.

A visual function of approximately 20/500 to 20/800 is required for a child to be able to establish eye contact, recognize facial features, and perceive gestures and facial expressions. If a child is lacking this degree of visual function, many aspects of social development can be affected, including attachment and play. Attachment (the ability to bond with parents) is delayed in blind children. Blind children play differently than normally sighted children. For example, children

with low vision tend to spend more time engaged in stereotypical behaviors, such as mouthing toys, and less time involved in functional play with toys.

Adaptive/self-help skills development

Adaptive/self-help skill development in young children refers to the development of skills to perform the activities of daily living such as feeding or eating, dressing and managing their own clothing, and personal hygiene skills such as washing, grooming, and toileting. Scores reflecting adaptive development skills on the Battelle Developmental Inventory are lower for children with severely impaired visual function than for children with better vision.

HOW IS VISION IMPAIRMENT IDENTIFIED AND DIAGNOSED?

Methods of detecting possible vision impairments are not designed to arrive at a formal diagnosis but rather to identify children who have an increased likelihood of vision impairment and therefore need further assessment.

- Some risk factors for possible vision impairment may be identified at birth. These risk factors include extreme prematurity and low birth weight, family history of blinding eye conditions (infantile cataracts, retinoblastoma, infantile glaucoma, or hereditary corneal dystrophy), and maternal intrauterine infections (Table 6, page 28).

- Eye examinations during routine health surveillance may yield findings that heighten concern about possible vision impairment. Sometimes, conditions such as congenital cataracts or congenital glaucoma are present at birth and can be recognized.

- Parental concerns about the child's vision can help identify risk factors. Sometimes, suspicion does not arise until the child demonstrates delays or disorders in motor or cognitive development. Some vision impairments are not discovered until a child reaches school age and is unable to do tasks requiring discrimination of fine details.

In an effort to identify children with vision impairment before they attend school, some vision screening programs have been implemented for preschool children. These screening programs are generally designed to detect amblyopia and risk factors for amblyopia. Children who do not pass the screening are referred for appropriate ophthalmic follow-up. Although many children who are referred for further assessment will turn out to have normal vision at the follow-

up testing, it is hoped that screenings will result in earlier detection of those children with vision impairment.

Specific measurement of visual acuity is usually not performed routinely for children before 3 or 4 years of age unless there is concern about possible vision impairment. Children younger than 5 or 6 years of age generally cannot be tested reliably with a standard Snellen letter chart because they need to know the alphabet. Other versions of a visual acuity eye chart (e.g., one with pictures or with only the letter E facing different directions) are typically used for children younger than 5 years old. Infants are usually tested using preferential looking techniques (see page 40). Sometimes, electrophysiological procedures, primarily visual evoked procedures, are also used (see page 41).

When vision impairment is suspected, it is often necessary to perform a variety of tests to determine the nature of the impairment and whether a specific cause or diagnosis can be identified. The specific tests depend on the child's age, as well as the suspected eye condition.

WHAT ARE COMMON INTERVENTIONS FOR CHILDREN WITH VISION IMPAIRMENT?

For infants and young children with vision impairment, interventions typically involve the following approaches:

- Correcting the child's vision to the extent possible

- Preventing or reducing the developmental problems that typically occur in children with limited vision

- Providing family education and support

For some children, vision may be improved or corrected by prescribing corrective lenses (glasses) or some other sort of assistive device to improve vision. The specific intervention used to correct vision impairment will depend on the nature and severity of the condition. For example, treatment for small cataracts may involve patching of the eye with the better vision to avoid amblyopia, while dense cataracts may require surgery.

Addressing developmental issues

For young children whose vision is not fully correctable with glasses, surgery, or other medical therapies, other interventions will be needed to address the developmental problems that typically occur in young children with vision impairment. For example, motor development and safe exploration of the

environment is often a major concern for children with vision impairment. Therefore, interventions often focus on orientation and mobility, and approaches to promote the child's interaction with the environment using what vision they have (residual vision) or other senses.

The intervention process begins with assessing the needs of the child and family. The assessment process determines interventions and establishes baseline information. Components of the assessment process usually include:

- A functional vision assessment of how the child uses vision
- An assessment of the developmental impact of the vision impairment
- Assessment of the child's orientation and mobility needs
- A health evaluation to determine whether the child has any associated health or developmental conditions, including hearing loss
- A learning media assessment to document how the child uses senses to gather information, comprehend, and learn
- Assessment of the family strengths and needs

A functional vision assessment is not a measurement of visual acuity or refraction but rather of how the child uses vision to interact and function with objects and people. Functional vision assessments are usually conducted prior to a developmental assessment so that the tests and testing materials can be adapted, if necessary, to accommodate a child's vision impairment.

Developmental issues may be compounded if the vision impairment is associated with another developmental disability. This is an important consideration because vision impairment is a relatively common occurrence in children with other disabilities.

Regardless of the interventions, parental involvement is an important component of promoting the developmental abilities of the child.

WHO ARE VISION CARE PROFESSIONALS?

Vision care professionals who may be involved in assessment and/or treatment for children with vision impairment include the following:

- **Ophthalmologists** are medical doctors (MD) who specialize in eye problems. They diagnose and treat eye conditions; test for visual acuity, visual field, and other aspects of visual status; prescribe glasses, low vision aids, and medications; and perform surgery. Pediatric ophthalmologists specialize in children's eye problems and vision.

- **Optometrists** are doctors of optometry (OD). Optometrists diagnose eye conditions; test for visual acuity, visual field and other aspects of visual status; prescribe glasses and low vision aids, and can prescribe topical medications (medications applied directly to the eye such as eye drops or ointments) for the treatment of eye conditions (the limitations on therapy vary from state to state). Optometrists do not perform surgery. Pediatric optometrists specialize in children's eye problems and vision. Low vision optometrists specialize in rehabilitation related to visual impairments.

- **Opticians** make glasses as prescribed by the ophthalmologist or optometrist. Opticians are not eye doctors nor do they examine eyes.

- **Orthoptists** are specially trained to measure eye muscle imbalance and provide specific treatment options for patients with strabismus and amblyopia. Orthoptists generally work under the supervision of a physician.

- **Ocularists** make artificial eyes.

- **Orientation and Mobility Specialists** (O&M specialists) specialize in the instruction of safe and efficient independent travel skills for individuals with visions impairments. They assess children's ability to use residual vision, or nonvisual compensatory techniques, to determine their location in space, plan how they will get somewhere, and move safely through their environment. O&M specialists provide direct instruction in travel-related skills. The long white canes used by the visually impaired are recommended by O&M specialists.

- **Teachers of the Visually Impaired** (TVI) work with children with visual impairments and their families on preacademic and academic skills. They assess a child's need for adaptive reading materials, provide support and instruction in preeducational and educational settings, and assist the family with school-related issues. A TVI is specially trained to teach Braille.

- **Rehabilitation Teaching Specialists** (RT) are teachers who specialize in teaching adapted daily living skills. They assess a child's ability to function in everyday activities such as dressing, eating, personal hygiene, and organization, and provide direct instruction in adapted techniques. They often work in conjunction with an occupational therapist.

Other professionals such as occupational and physical therapists, speech language pathologists, etc., may also be involved in the assessment and intervention process depending on the strengths and needs of the individual child and family.

CHAPTER III: ASSESSMENT

IDENTIFICATION AND ASSESSMENT

In this guideline, a vision assessment method is broadly defined as any assessment test, measure, or procedure that can be used to identify or assess infants and young children with vision impairment. Vision impairment is the loss of some aspect of vision (sense of form, color, or light) that reduces a child's ability to see. Vision impairments range in severity from mild vision loss to total absence of light perception. Severe vision impairment may be fairly easy to detect, but many vision impairments are not obvious.

Assessment methods include standardized and nonstandardized tests (often based on history, direct observations, and/or physical findings), as well as the use of sophisticated technology such as photoscreeners or imaging tests. Routine vision screening, as is usually administered to most infants and young children, can be effective for identifying many eye and vision problems, but there is no method that accurately identifies all young children with vision impairment.

Because vision plays such an important role in a child's early development, it is important to identify children at risk for vision impairments as early as possible. Some vision impairments may be easily corrected with glasses, surgery, or other medical intervention, but others may not.

Early recognition of vision problems and appropriate early intervention may help to maximize the child's general development and may promote better long-term functional outcomes for both the child and family.

GENERAL APPROACH

Identifying initial concerns about a possible vision impairment

It is important for professionals and parents to recognize that there are several ways children with vision impairment are first identified. These may include:

- Identification of risk factors (e.g., prematurity or perinatal problems)

- A parent's concern about the child's vision or some other aspect of the child's development

- A health care provider's or other professional's concern about the child's vision

Parental concern can often be a reliable indicator of a vision problem. Therefore, during a routine evaluation of children, it is recommended that health care

professionals ask parents about the child's vision (Table 7B, page 30). Examples of such questions include:

- Do you think the child sees normally?

- Do you have any concerns about the child's vision?

- Does the child tend to close one eye in sunlight?

- Does the child tend to repeatedly hold his/her head in the same position?

- Does the child tend to object to one eye being covered?

General considerations for the assessment process

When assessing young children, it is important to understand the whole child and to consider any factors that may have an impact on the child's performance during the assessment process. Such factors may include the child's schedule, overall health status, the setting of the assessment, and the child's mood and temperament (fatigue, illness, shyness, excitement) at the time of assessment.

It is recommended that the setting where the assessment is conducted be appropriate to the developmental stage of the child and be comfortable for both parent and child. It is also recommended that assessment materials and strategies be developmentally appropriate.

Infants with vision impairment often have delays in other developmental domains that need to be identified and addressed with specific interventions. Additionally, some vision problems are associated with other conditions, such as cerebral palsy or Down syndrome. Therefore, there may be many different professionals involved in an ongoing process of assessment and intervention.

Considerations for professionals

It is important for health care professionals to understand typical visual development in young children in order to:

- Facilitate recognition of potential vision problems

- Make appropriate observations about the child's development

- Initiate appropriate methods for ongoing monitoring (developmental surveillance)

- Give accurate information to parents and families

- Assist in making appropriate referrals

- Facilitate appropriate intervention strategies

In order to assure quality and consistency, it is recommended that professionals assessing young children with vision impairment:

- Have experience and expertise in their specialty and in assessing young children with vision impairment

- Use assessment instruments designed for use with children with vision impairment as well as observational information

- Use procedures that are reproducible by other professionals

Ongoing monitoring and periodic reassessment

It is important that assessment be viewed not as a single event. After the initial assessment, ongoing monitoring and periodic reassessment of the child's progress over time is important.

IDENTIFYING YOUNG CHILDREN WITH VISION IMPAIRMENT

Risk factors, clinical clues, and general surveillance for vision impairment

As used in this guideline, a ***risk factor*** is an indicator that increases the possibility that the child either has or will develop vision impairment (Table 6, page 28). A ***clinical clue*** is a possible early sign or symptom of vision impairment (Table 7A, 7B, 7C; pages 29, 30, 31).

The presence or absence of risk factors or clinical clues is not by itself enough to establish that vision impairment exists. Risk factors and clinical clues are sometimes seen in children who do not have vision impairment. If a child does have a risk factor or clinical clue of possible vision impairment, it merely provides an indication that further assessment may be needed. Some children with vision impairment do not have any obvious risk factors or clinical clues.

General surveillance for vision impairment

The term surveillance is used to describe a flexible and continuous process in which knowledgeable professionals monitor a child's health and developmental status, usually during the provision of routine health care services. Surveillance includes asking about and attending to parents' concerns, obtaining a relevant health and developmental history, observing the child, and sharing opinions and concerns with other relevant professionals.

Surveillance for vision problems for infants and young children usually includes an inspection of the eyes, tests for ocular motility (movement) and eye muscle imbalance, ophthalmoscopic examination, and tests for visual acuity as appropriate for the age of the child. Surveillance for preschool children may also include an evaluation of stereoacuity and color vision.

> **Early Intervention Policy** ❖ Monitoring and developmental surveillance for children at risk for vision problems is generally conducted within the context of the child's health care program. To be eligible for the Early Intervention Program, a child must have either a developmental delay that meets the state definition of developmental delay or a diagnosed condition that has a high probability of resulting in developmental delay (see Appendix B).

Table 6: Risk Factors for Vision Impairment in Young Children

Risk factors for vision impairment in young children include:

Prenatal and birth history

- Fetal alcohol syndrome

- Fetal distress or birth trauma/hypoxia (especially if birth asphyxia)

- Intracranial hemorrhage

- Intrauterine exposure to toxins

- Intrauterine infection

- Prematurity, especially low birth weight babies (less than 2000 gms.)

- Very low birth weight infants (less than 1500 gms.), low Apgar (a score of 5 or less at 5 minutes), and brain lesion noted on imaging (Pinto-Martin)

Congenital conditions

- Albinism

- Cerebral palsy

- Chromosomal abnormalities, such as Down syndrome

Other

- Acute illness such as meningitis or encephalitis

- Child abuse (especially head trauma such as shaken baby syndrome)

- Family history of conditions causing blindness or severe visual impairment (e.g., congenital cataracts, retinoblastoma, and certain metabolic and genetic diseases)

- General developmental delay or mental retardation

- Head trauma

- Hydrocephalus

- Infectious disease (e.g., toxoplasmosis, cytomegalovirus, herpes simplex)

- Periventricular Leukomalacia (PVL)

Adapted from: Jaafar 1996, Menacker 1993

| **Table 7A:** | **Clinical Clues of Possible Vision Impairment: Physical Exam Findings** |

Physical Exam Findings

- Abnormal head posture
- Abnormal craniofacial features (e.g., microcephaly, ptosis)
- Abnormal pupil response
  - Abnormal red reflex
  - Asymmetrical Bruckner test
  - Afferent pupil response
- Absence or abnormality of optokinetic nystagmus (OKN) after age 6 months
- Coloboma
- Corneal opacification or congenital cataracts
- Asymmetrical corneal light reflex
- Direct observation of an eye turn
- Delayed, absent, or abnormal visual fixation/following
  - Absence of any fixation at birth
  - Has not developed good fixation (saccade) by 6-9 weeks
  - Has not developed good following (pursuit) by 2-3 months
- Iris abnormalities
  - Albinism (findings of albinism such as transillumination)
  - Aniridia (absence of the iris)
- Nystagmus (other than reflex nystagmus such as OKN)
- Strabismus

Adapted from: Katsumi 1998

Table 7B: Clinical Clues of Possible Vision Impairment: Visual Behaviors

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Visual Behaviors

Information about visual behaviors that may indicate a possible vision problem can be obtained from observation of the child, from expression of parental concern about the child's vision, or from information provided by the parent(s) in response to specific questions. Examples of clinical clues of a possible vision problem include:

- Photophobia (avoidance of bright light/squints in bright light/preference for dim light)
- Stares at bright lights
- Closes one eye
- Nondirected or "roving" eye movements
- Does not seem to respond to parent's face
- Does not seem to imitate parent's facial expression
- Does not seem to follow movement of objects or people
- Does not reach for bottle when presented quietly
- Does not seem to show interest in toys/objects within reach
- Does not seem to show visual interest in television
- Does not seem to show interest in books
- Seems to have limited interest in different kinds of toys
- Does not seem to recognize colors or shapes
- Bumps into objects
- Visual self-stimulatory behaviors (e.g., eye rubbing, pressing, or poking)

Adapted from: Katsumi 1998

Table 7C: **Clinical Clues of Possible Vision Impairment: Visual Developmental Milestones**

The age ranges for the visual developmental milestones are approximate and will vary somewhat among children. Because many of the visual milestones are dependent on other areas of development (such as development of cognitive and motor skills), a delay or failure to achieve a visual developmental milestone may be an indication of a vision problem or it may be an indication of some other developmental delay.

Failure to achieve the following milestones may be an indication of a vision problem.

By 6 weeks:
- Stares at surroundings when awake
- Momentarily holds gaze on bright light or bright object
- Blinks at camera flash
- Eyes and head move together

By 24 weeks:
- Eyes begin to move more widely with less head movement
- Eyes begin to follow moving objects or people (8-12 weeks)
- Watches parent's face when being spoken to (10-12 weeks)
- Begins to watch own hands (12-16 weeks)
- Eyes move in active inspection of surroundings (18-20 weeks)
- Looks at hands, food, bottle while sitting(18-24 weeks)
- Begins to look for and watch more distant objects (20-28 weeks)

By 48 weeks:
- May turn eyes inward while inspecting hands or toy (28-32 weeks)
- Eyes more mobile and move with little head movement (30-36 weeks)
- Watches activities in the environment for longer periods of time (30-36 weeks)
- Visually attends to dropped toys (32-38 weeks)
- Visually inspects toys while holding (38-40 weeks)
- Creeps after favorite toy when seen (40-44 weeks)
- Sweeps eyes around room to see what's happening (44-48 weeks)
- More and more visual inspection of objects and persons (46-52 weeks)

By 18 months:
- Uses both hands and visually steers hand activity (12-14 months)
- Visually interested in simple pictures (14-16 months)
- Often holds objects very close to eyes to inspect (14-18 months)
- Points to objects or people using words "look" or "see" (14-18 months)
- Looks for and identifies pictures in books (16-18 months)

Table 7C: Clinical Clues of Possible Vision Impairment: Visual Developmental Milestones

By 36 months:
- Smiles, face brightens when views favorite objects and people (20-24 months)
- Likes to watch movement of wheels, egg beater, etc. (24-28 months)
- Watches own hand while scribbling (26-30 months)
- Visually explores and steers own walking and climbing (30-36 months)
- Watches and imitates other children (30-36 months)
- Begins to keep coloring on the paper (34-38 months)
- "Reads" pictures in books (34-38 months)

Adapted from: A Reference Guide for Preschool Children's Vision Development 1995
(Continued from previous page)

Considerations for Young Children with Specific Risk Factors for Vision Impairment

Low birth weight premature infants

One of the commonly identified risk factors for vision impairment is prematurity. In very low birth weight infants (less than 1500 gm), it is important to look for brain lesions using neuroimaging techniques such as MRI and cranial ultrasound (see page 42). It is recommended that low birth weight infants with documented brain lesions (confirmed by neuroimaging in newborn period) need enhanced surveillance for vision impairments and other developmental problems through at least 2 years of age.

Retinopathy of prematurity (ROP)

One of the specific risks for vision impairment for children born prematurely is retinopathy of prematurity (ROP). Premature infants are at high risk for vision problems because the retinal blood vessels do not attain maturity until the ninth month of gestation. Therefore, the retinal blood vessels of the premature infant have not completely developed. It is important to monitor children with ROP because they are at increased risk for vision impairment. The more severe the ROP, the more likely there will be related vision impairment. Although premature infants are at risk for ROP and permanent visual impairment, visual outcomes for these children have improved in recent years because of new methods for identifying and treating ROP.

Cortical visual impairment

Another common cause of vision impairment in young children is damage to the visual cortex in the brain or to the visual pathways. Cortical visual impairment (CVI) is caused by lack of oxygen at birth (anoxia), head injury, infections of the central nervous system (e.g., encephalitis and meningitis), or genetic malformation.

Cortical visual impairment is often associated with pervasive neurological disorders such as cerebral palsy or epilepsy, and children with CVI usually have multiple impairments.

Periventricular leukomalacia (PVL)

It is important to follow closely preterm infants with PVL because they have a high likelihood of having vision impairment and/or other developmental problems.

It is important to recognize that there is a distinction between moderate and severe PVL, and that the severity of the PVL is correlated with the severity of the visual impairment. If the child has PVL noted on MRI (see page 42) but there are no visual cortex abnormalities, a better outcome is predicted. When assessing children with vision impairment related to PVL, it is important to be aware that both the vision impairment and the PVL can affect the development of motor skills.

Perinatal Brain Lesion

It is important to recognize that even if the child has a brain lesion on neuroimaging at birth, a large proportion of these resolve over time with no significant visual impairment. At the time of birth, it is generally not possible to predict which children with perinatal brain lesions will have vision problems. However, children at higher risk for vision problems generally include children who have either neuroimaging evidence of brain lesion and later develop cerebral palsy or a lesion in basal gangli.

Absence or asymmetry of optokinetic nystagmus (OKN)

It is important to recognize that absence or asymmetry of OKN in any child after the age of 6 months is a clinical clue of poor vision and possible neurodevelopmental problems, and is a reason for referral to an eye care professional for further assessment.

Table 8: General Vision Surveillance: The Physical Examination

Components of the eye exam that can be performed as part of routine health care exams by the primary care provider:

- *Fixation and following:* Fixation and following involves visually following a moving target, such as a bright-colored toy or a human face, slowly to the right and to the left, and observing whether the infant's eyes turn toward the object and follow its movement. This is one of the most common tests to assess general visual function.

- *Red reflex test*: The red reflex is the red light reflection seen when examining the eye with an ophthalmoscope. This test is used to determine whether there is an opacity (cloudiness) of the cornea, a cataract, or a retinal detachment or disorder.

- *Binocular red reflex*: The Bruckner test is a comparison of the red reflexes when viewed from both eyes at the same time. This test is used to assess symmetry of alignment and refractive errors of the eyes.

- *Corneal light reflex test*: The corneal light reflex is a reflection of light from the cornea. If the eyes are aligned, the reflection will be symmetrical. This test is used to determine whether there is ocular misalignment (strabismus).

- *Pupillary examination*: Pupillary reaction is evaluated by testing constriction of each pupil both when it is stimulated directly by light and when the other eye is stimulated by light (consensual light reflex), when accommodating to near vision (accommodation reflex), and when the illumination is reduced.

- *External examination of the eye*: External examination of the eye is a general inspection of the eye including the orbits, globes, eyelids, eyelashes, tear sacs, and conjunctiva. A more detailed evaluation of the anterior segment of the eye using oblique illumination is then conducted, focusing on the cornea, the anterior chamber, and the iris. The purpose of this examination is to look for structural defects, foreign bodies, abrasions, and inflammatory signs.

Table 9: General Vision Surveillance: Tests of Vision

The following are other general tests of vision and examinations of the eyes that are often included as a part of general surveillance for vision impairments (depending on the age of the child).

Visual acuity

Visual acuity is a measure of how clearly a person can see at different distances. In older children and adults, acuity is usually determined by having the person read letters of various sizes at a set distance from a standardized chart (Snellen chart). Normal visual acuity (20/20 vision) means that a person can see at 20 feet what the normal eye would see at that distance.

Visual acuity improves over the first few years of life. At birth, the visual acuity of the immature visual system is less than 20/200, but this usually improves to 20/20 within the first 3 years. Visual acuity generally increases rapidly during the first 6 to 8 months of life and then more slowly for the next two years. At 36 months, visual acuity is still developing.

Methods for measuring visual acuity in infants and young children depend on the child's age and ability to cooperate.

- The most common test of visual function in young infants is an assessment of their ability to fixate and follow a target. The fix-and-follow reflex can usually be observed by the time an infant is approximately 6 weeks of age.

- Common methods for measuring visual acuity for children 2½ to 3 years of age include the use of a schematic picture or other simplified eye chart. The Tumbling E-test or HOTV test is often used for children 3 to 4 years of age. An adult-type Snellen chart is generally not used until children are approximately 5 or 6 years of age and know their letters.

- Sometimes the visual acuity of preverbal children is tested using more elaborate techniques such as preferential looking, optokinetic nystagmus, or electrophysiological methods.

Visual field

A person's visual field is the area within which objects may be seen when the eye is observing a fixed object. The visual field can then be mapped to determine its range and whether there are any abnormal blind spots (scotoma). The size of the visual field is measured in degrees. For infants and young children, the examiner observes the child's response to a familiar object, such as a bottle or favorite toy, when it is brought into each of the four quadrants of the visual field. In older children, the examiner asks the child to communicate verbally when an object is visible.

Ocular motility

Ocular motility is a measure of how the eyes move when a person follows an object into the various positions of gaze. Assessment of ocular motility includes testing movements of each eye individually and then testing how the two eyes move together when following an object. Alignment is judged by the symmetry of the corneal light reflexes and by the response to alternate occlusion of each eye. Strabismus (the misalignment of the visual axes of the two eyes) is often detected by measuring ocular motility.

Screening for Amblyopia and Refractive Errors

The purpose of vision screening of young children is to identify risk factors or conditions that would likely result in poor vision if not identified and treated. Screening can be designed to test broadly defined groups of children, such as preschool children, for a specific condition, or it can be used more selectively to screen children when a heightened concern for vision impairment has already been identified. Nonspecific vision screening generally occurs during routine health care visits as a part of general surveillance for vision problems (page 26).

Conditions that can result in poor vision include:

- Lens opacities (cataracts)

- Significant visual acuity deficit (due to significant refractive error)

- Significant difference in refractive error between the eyes

- Significant difference in visual acuity between eyes (amblyopia)

- Misalignment of the eyes/eye turn (strabismus)

Screening for amblyopia

Functional amblyopia is an unexplained reduction in clearness of vision that cannot be corrected by glasses or contact lenses. Amblyopia is sometimes incorrectly referred to as "lazy eye" because it is often associated with strabismus in which the two eyes are not symmetrically aligned (one eye appears to be "lazy"). Children with strabismus often develop amblyopia in the affected eye.

With functional amblyopia, there is no visible organic lesion or pathological basis for the vision loss. Amblyopia occurs in early childhood, usually by the age of three years. Amblyopia usually occurs in only one eye, and young children tend to be able to compensate for this. For this reason, amblyopia is rarely obvious.

By some estimates, amblyopia affects more than 2% of the general population. Untreated, amblyopia can result in severe loss of vision in the affected eye. However, when recognized early, amblyopia can usually be effectively treated. Amblyopia is most treatable when it is identified and treated before the visual system has matured. Although visual maturation is generally thought to occur by approximately 7 years of age, there may still be some plasticity of the visual system well beyond childhood.

Amblyopia is a correctable vision condition, and developmental delays are generally not associated with amblyopia in early childhood. Therefore, young children with amblyopia are generally not eligible for the Early Intervention Program. However, it is important to identify and appropriately treat children with correctable vision problems to prevent future deterioration of vision.

Using photo-technology to screen for amblyopia and refractive errors

Photoscreeners (sometimes called photorefractors) are special cameras that take a picture of the eye at a single point in time. Information can be obtained from the photograph about refractive errors (nearsightedness or farsightedness), difference in eye focus, alignment, eye turn, and cataracts. Because the photography procedure is noninvasive, requires the child to focus only briefly for the photograph, and can be performed by technicians, photoscreeners are possible vision screening tools for amyblyogenic disorders in young children.

Another type of device, the autorefractor, provides a more direct measurement of the refractive level of the eye. It is similar to retinoscopy, where the light is adjusted until the focus is obtained. This type of device is not generally used for screening but is involved in the assessment by an eye care professional.

Considerations for use of photo-technology

Photorefractors are generally more difficult to use with children under 36 months of age because children must be able to maintain a still position and fixate on an object while the picture is taken. It is recommended that photoscreeners not be used for widespread screening of young children (birth to 3 years) because it is a relatively expensive method and has not demonstrated that it reliably identifies children who need further evaluation.

It is important to recognize that autorefractors, while not useful for overall screening for refractive errors in young children (birth to 3 years), may be a reliable method for detecting astigmatism (one type of refractive error).

Important considerations for screening programs

Important considerations when designing a screening program or selecting a screening instrument include:

- Effectiveness at correctly identifying the condition (sensitivity/specificity)

- Risk of harm or side effects

- Ease of application

- Reproducibility and interrater reliability

- Training requirements

- Availability

- Acceptability

- Cost effectiveness

ASSESSMENT OF VISUAL STATUS

Ophthalmic Examination

The ophthalmic examination is intended to further evaluate children when vision impairment is possible because of risk factors and clinical clues, parents' or professionals' concerns, and/or positive screening test results.

The uses of ophthalmic evaluation include:

- Determining whether vision impairment is present

- Establishing a specific diagnosis and assessing the severity and specific attributes of the vision impairment

- Determining whether intervention is indicated and helping plan intervention strategies

> **Early Intervention Policy** ❖ An ophthalmic examination should be part of an early intervention multidisciplinary evaluation if a child is suspected of having a vision impairment.

Table 10:   Ophthalmic Exam: Components of the Basic Exam

Examination of the interior of the eye

An ophthalmic examination involves dilating the pupil and using a magnifying instrument called the ophthalmoscope to look at the interior of each eye.

Biomicroscopy (slit lamp examination)

Biomicroscopy provides a highly magnified view of the various structures of the eye. This procedure is used to identify and localize lesions, evaluate trauma, examine for inflammation of the iris, and diagnose metabolic diseases.

Refraction

Refraction is the optical focusing of the eye. The refractive state of the eye and the amount of correction needed can be measured by retinoscopy, which is an objective technique that involves projecting light into the eye and measuring the reflected light rays. Because no subjective judgments are required, retinoscopy can be used in children of any age.

In young children, eye drops are usually administered when performing retinoscopy. The drops dilate the pupil and prevent the pupil from contracting.

In young children, there are three types of refractive errors:

▪ In nearsightedness (myopia), the light rays come into focus in front of the retina. Objects in the distance are blurred.

▪ In farsightedness (hyperopia), the light rays encounter the retina before they are in focus. This is a normal condition in young children, and most are able to compensate for normal levels of hyperopia.

▪ In astigmatism, there is blurring or distortion of vision at all distances due to the aspheric (oval rather than round) curvature of the cornea or lens. Astigmatism may be present alone or combined with myopia or hyperopia.

Tonometry

Tonometry is a procedure that measures intraocular pressure. It may be performed in several different ways and may require the child to be sedated. The purpose of this examination is to detect glaucoma, a disease characterized by increased intraocular pressure.

Table 11:   Vision Assessment Approaches: Test of Visual Acuity

Preferential Looking Technique

Preferential looking techniques are used to assess visual function in preverbal or nonverbal children. The infant is presented with slides containing a visual target (a picture or design) in one location on the screen and a gray field in a different location. The observer, without the knowledge of the position of the grating, records the side of the screen that the infant is looking at. Grating acuities are recorded in cycles per degree (CPD) at a specific distance (Birch 1988).

Teller Acuity Cards (TAC)

One of the most common preferential looking techniques is Teller Acuity Cards. The child is presented with a series of high contrast cards, each of which contains a black and white square-wave grating and a uniform gray field of matched average luminance. An observer judges whether a child can resolve the grating on the card by recording the child's visual behavior and any additional behaviors towards the card. The spatial frequency at which the child can resolve the grating is recorded in cycles per degree for specific distances (Hall 2000).

Stereoacuity Tests

Stereoacuity tests measure binocular vision (how the brain uses vision using both eyes together).

Random Dot E Stereotest (RDE)

The Random Dot E Stereotest is performed using plates that contain random dot patterns presented to the child at a specific distance. The child looks or points to the card containing a figure E, visible when viewed binocularly (with both eyes) through special Polaroid glasses.

Titmus Fly Stereotest

The Titmus Fly Stereotest is performed by presenting a picture of a large fly that is viewed using special binocular glasses. With adequate binocular vision, the wings of the fly appear 3-dimensional, which generally evokes a response from the child.

Preferential Looking Techniques

Preferential looking is a valid test to measure visual acuity and detect vision deficits in preverbal children. When preferential looking techniques are used, it is important to familiarize the child with the test and then ascertain that he or she is responding appropriately before making an assessment of the child's acuity.

Teller Acuity Cards (TAC)

As a gross assessment of visual status, TAC can provide a relatively accurate assessment of visual acuity in preverbal children as young as 4 months of age. However, TAC tend to be better at identifying children with normal vision than identifying children with abnormal vision.

TAC scores provide information about how the child is doing at the time of the test. It is recommended that children who have TAC test results showing low visual acuity and have no other abnormal finding on the ophthalmic exam receive enhanced vision surveillance and periodic vision testing.

If a child is not able to respond to other tests, a modified TAC test using pointing may be useful for identifying amblyopia and obtaining a gross estimate of visual acuity.

Interpreting results from TAC is more subjective than some other tests because it requires interpretation of the child's behavior. Interrater reliability is therefore an issue with TAC. It also is important to remember that other impairments, such as motor or cognitive impairment, may influence the child's performance and the accuracy of the results.

Random Dot E Stereotest

Children with a normal response on the Random Dot E test have a high likelihood of having good visual acuity, good alignment (no strabismus), equally good vision in both eyes (no amblyopia), and good ability to use both eyes at the same time.

Random Dot E test can be used as an indicator of binocular vision status in preverbal children as young as 6 months. This test is a relatively good predictor when the results are normal. In preverbal children, this test can be conducted using preferential looking techniques.

The Random Dot E test may be useful as a test of binocularity, but it is recommended that it not be used as the only test. Some children with poor vision will be able to pass this test.

Electrophysiological Assessment Methods

Neuroimaging

Some vision impairments that occur in early childhood are the result of either brain injury or malformation of some part of the brain and can often be

visualized with neuroimaging techniques. There are several ways to image the central nervous system:

- Conventional **x-ray of the skull** is generally not useful for detecting conditions related to vision impairment.

- **Ultrasound** can sometimes be useful for diagnosing certain conditions that may be associated with vision impairment, such as brain lesions. Ultrasound is most useful in the newborn period because it is inexpensive, portable, and gives an instant assessment.

- **Computerized Axial Tomography (CT)** can scan an entire brain in a few minutes. The patient needs to lie motionless for the procedure; however, sedation is rarely needed. It is expensive but far less expensive than Magnetic Resonance Imaging.

- **Magnetic Resonance Imaging (MRI)** is the most sophisticated method available to visualize the central nervous system. All areas of the brain and all lesions are visualized well. The patient is required to stay motionless for a prolonged period of time. Therefore, sedation is often required for the young or developmentally delayed child. The expense is considerable but is usually covered by insurance when there are clinical indications for its use.

Electrophysiologic tests

- **Electroretinogram (ERG)** is a record of the electrical impulses in the retina produced by visual or light stimuli. Certain retinal disorders give characteristic ERG results.

- **Evoked Potentials** are responses in the appropriate receptor area in the brain to the stimulating sensory organs (eyes or ears) or peripheral nerves. Responses are graphed using computerized averaging methods.

Early Intervention Policy ❖ Medical tests are not reimbursable under the NYS Early Intervention Program unless the test is determined to be necessary to establish a child's eligibility for the program.

Visual Evoked Potential (VEP)

Because of its limited usefulness, it is recommended that VEP be ordered only after the child has had an eye exam, and only for children who seem to have a normal eye exam administered by an eye care professional.

It is important to recognize that:

- Results from VEP in the first 6 months are difficult to interpret because of maturational changes that usually occur in the child's nervous system

- A normal VEP can be a good predictor of normal neuromotor outcome, but an abnormal VEP result is not necessarily predictive of poor prognosis

- For infants who have normal eyes on examination but who are apparently blind or severely visually impaired, a normal VEP is an indicator of likely improvement in vision. However, an abnormal VEP does not necessarily indicate a poor prognosis.

Assessment of Visual Function

An assessment of visual function assesses how the child uses vision to interact with the environment. This is an important component of the assessment process for young children with vision impairment. Areas addressed in such an assessment usually include optical and optical/perceptual discrimination, recognition and identification, visual memory, spatial perception, and visual-motor coordination.

The assessment of visual function relies on a written description of the child's use of vision rather than on a standardized test. Examples of published checklists and protocols to assess functional vision include:

- *Vision Assessment and Curriculum Reference* (Utah School for the Blind)

- *Peabody Model Vision Project: Functional Vision*

- *Look at Me: A Resource Manual for the Development of Residual Vision in Multiply Impaired*

- *Individualized Systematic Assessment of Visual Efficiency (ISAVE)* (American Printing House for the Blind)

It is important to conduct the visual function component before assessing other developmental domains such as cognition and sensorimotor development. This will allow the evaluator doing the developmental assessment to present items they know the child can understand and position the child and materials in a way that optimizes the child's visual potential.

It is, however, important to consider the child's cognitive, communication, and sensorimotor development level when assessing visual function. This is important because the ability to use vision is related to cognitive development

and delays in other areas of development can impact the child's ability to respond to assessment items. It is important to consider this information when assessing visual function and when planning intervention strategies.

Table 12:   General Components of an Assessment of Visual Function

An assessment of visual function typically includes the examiner's qualitative observation or parent's report of:

- Fixation (the ability to hold a stationary object in gaze)
- Gaze shift
- Scanning (the ability to search an area visually)
- Tracking (the ability to hold a moving object in gaze)
- Visually directed reach and grasp
- Eye movements
- Separation of eye and head movements
- Spatial awareness (awareness of placement of self in relation to other things in the environment)
- Awareness of visual field (visual perception in all quadrants of the visual field)
- Depth perception
- Observation of detail
- Matching and identification of objects and pictures (including shape, size, color)
- Visual motor (e.g., midline hand play, object manipulation, bead stringing, etc.)
- Eye preference
- Figure-ground discrimination
- Convergence and eye tearing skills (the ability of the eyes to aim, move, and work as a coordinated team)

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early intervention

Early Intervention Policy ❖ The following qualified personnel in the Early Intervention Program can perform visual function assessments: physicians, physician assistants, nurse practitioners, teachers of blind and partially sighted, certified orientation and mobility specialists, and certified low vision specialists.

DEVELOPMENTAL ASSESSMENT

General Approach to Developmental Assessment

Acquisition of developmental skills in young children with vision impairment is often delayed and usually differs in sequence from typically developing children. A major source of sensory information is either reduced or not available, which usually results in a tendency for visually impaired children to withdraw from interacting with the immediate environment. This kind of interaction is an important component of how young children learn and grow developmentally.

Children with vision impairment have a wide range of visual abilities and developmental profiles. For example, children with similar visual abilities will not necessarily have the same developmental profiles. Some children will learn picture identification and even letter identification in their first three years. Others will have to rely on touch and sound for learning throughout their lives.

Importance of the developmental assessment for children who are visually impaired

It is important that all young children with vision impairment have ongoing age-appropriate developmental monitoring and assessment. Developmental assessment includes evaluation of cognition, communication (including an objective test of hearing), behavior, social interaction, sensory and motor abilities, orientation and mobility, and adaptive/self-help skills.

Early Intervention Policy ❖ The multidisciplinary evaluation for children in the Early Intervention Program must assess all five areas of development (cognitive, communication, physical, social/emotional, and adaptive). The multidisciplinary evaluation is provided at no cost to parents

Developmental assessments are important for children with vision impairment because they can:

- Help identify possible developmental problems

- Provide an objective description of the child's abilities (a functional assessment)

- Aid in planning for appropriate intervention strategies
- Provide a baseline for measuring progress and effects of interventions

The developmental assessment process

It is recommended that the developmental assessment not be viewed as a single event. It is important for there to be ongoing monitoring and periodic reassessment of the child's developmental progress over time.

Developmental assessments can be performed by a variety of professionals in a number of settings. It is also important that the developmental assessment include multiple testing modalities (such as pictures, objects, sounds, textures, vibration, and movement) and assessment approaches (such as assessment instruments, observation, and parent report).

It is important to recognize that the order in which the comprehensive eye exam and general developmental assessment are conducted may vary. These assessment processes may occur in several phases and may involve multiple professionals as well as the child's parents. It is recommended that a parent or other primary caregiver be present for the formal assessment and that information from the parent report in the assessment be included.

General developmental assessment tests

It is important to understand that there are no general developmental assessments specifically designed for children with vision impairment. Developmental assessment tests (Table 13, page 48) are generally not normed for children with vision impairment, and interpretation should be made with caution. It is important to note any modifications to the test and whether those modifications were suggested by the developers of the test.

It may be useful to use general tests of development that are not specific to vision impairment (e.g., Hawaii Early Learning Profile, HELP) as well as tests developed specifically for children with vision impairment (e.g., Oregon Project for the Blind and Visually Impaired). Comparing the results from both types of tests provides a more detailed description of the child's abilities.

Developmental Assessment Tests: Types of Tests

Standardized test

A test in which the procedures for administration, the materials used during the test, and the means of scoring the results are consistent.

Norm-referenced test

A test in which an average score has been determined for typical performance of a defined group (e.g., children with vision impairment). The tested individual's score is being compared with the average score of the normed group.

Criterion-referenced test

A test that measures whether particular criteria or standards of performance (determined by the test creator) are met without reference to a normed group.

Curriculum-based assessment

A nonstandardized checklist (sometimes based upon developmental milestones) that determines the skill level of a child on a developmental continuum without numeric scoring.

Table 13:   General Developmental Assessment Tests

Standardized tests

Not designed or normed for visually impaired

Bayley Scales of Infant Development II (BSID-II)	Cognitive, motor, and behavior	Birth - 42 mos.
Mullen Scales of Early Learning	Cognitive and motor	Birth - 5 yrs.
Pediatric Evaluation of Disability Inventory (PEDI)	Self-care, mobility, and social function	6 mos. - 7 yrs.

Some items adapted for visually impaired

Battelle Developmental Inventory (BDI)	Personal-social, adaptive, motor, communication, and cognition	1 mo. - 9 yrs.

Tests normed specifically for visually impaired

The Maxfield-Bucholz Social Maturity Test for Visually Impaired and Blind Preschoolers	Social, self-help, fine and gross motor, and general adaptive	Birth - 5 yrs.

Criterion-referenced and curriculum-based tests

Not designed for visually impaired

Hawaii Early Learning Profile (HELP)	Social, cognitive, motor, language, and adaptive sensory	Birth - 36 mos.

Adapted for visually impaired

Carolina Curriculum for Infants and Toddlers with Special Needs	Social, cognitive, motor, language, and adaptive sensory	Birth - 24 mos.

Designed for visually impaired

Developmental Guidelines for Infants with Visual Impairments	Social/emotional, communication, cognitive, fine and gross motor, and visual function	Birth - 24 mos.

Table 13:   General Developmental Assessment Tests

Functional Scheme: Functional Skills Assessment	Fine and gross motor, perceptual, spatial and object perception, social and emotional perception, language, play, and daily living skills	Birth - 48 mos.
Oregon Project for the Blind and Visually Impaired	Cognitive, language, visual, fine and gross motor, socialization, compensatory skills, and self-help	Birth - 6 yrs.
Parents and Visually Impaired Infants (PAVII)	Social, cognitive, motor, language, and adaptive	Birth - 24 mos.
Preschool Orientation and Mobility Screening	Gross motor, body image, spatial concepts, orientation, mobility	Birth - 6 yrs.

(See Appendix A for additional information about Developmental Assessment Tests.)
(Continued from previous page)

Components of the developmental assessment

The two important components in assessing the development of children with vision impairment are the general development (cognitive, communication, sensory-motor, social/emotional, adaptive/self-help) and use of vision or compensatory nonvisual skills (how the child uses vision or nonvisual techniques in the natural environment). It is important for the developmental assessment to include both descriptive information and test scores.

It is recommended that a developmental assessment for a young child with vision impairment provide an adequate functional profile of all developmental domains. Important components of a developmental assessment include both formal and informal assessments of:

- Family resources, priorities, and concerns

- Medical history, including hearing status

- Appropriate tests, as needed, of:
  - Cognitive ability
  - Communication (receptive and expressive language)

- Motor skills, fine and gross motor
- Orientation and mobility
- Use of vision (visual functioning)
- Nonvisual compensatory skills
- Sensory processing abilities
- Adaptive/self-help skills
- Social/emotional functioning

It is important that the developmental assessment include observational information obtained in the child's natural environment (informal and structured play and parent-child interactions) as well as parent reports and interviews to elicit concerns and information about the child's early development and current level of functioning.

Conducting the assessment

When conducting a developmental assessment, it is important to recognize that there are general as well as individual differences between children who have useful vision and children who do not have useful vision. What may be appropriate for one child may not be appropriate for another.

It is important to recognize that no child is "untestable." Some tests, however, may not be appropriate for some children. It is important to use appropriate testing materials and strategies for each child.

Considerations for planning the setting for the assessment include:

- Having minimal distractions
- Including a variety of test items, with some provided by parents
- Conducting the assessment in a place that the child associates with activities being assessed
- Having variable or a variety of lighting
- Using both familiar and unfamiliar items of different sizes and levels of difficulty

Before beginning the assessment, it is important for the professional conducting the assessment to obtain information about the child's eye condition, severity of vision loss, amount of residual vision, and how the child uses vision in functional settings including home, familiar areas outside the home, and unfamiliar areas. It is also important to have information about any health/developmental/background issues that might have an impact on the child's development.

Parent involvement in the developmental assessment

It is recommended that parents or caregivers be involved in the assessment process in order to provide information about their observations of the child's skills and typical activities and level of assistance required.

Assessing developmental milestones

It is important to assess a child's progress in reaching developmental milestones because it gives parents, professionals, and others caring for the child a better understanding of the child's developmental status. It also helps when making appropriate decisions about the focus, timing, and sequence for interventions. It is important to recognize that children will attain specific developmental milestones at different times. It is also important to remember that most developmental assessment tests have not been standardized for children with vision impairment and may not accurately reflect the child's true developmental status.

It is also important to compare the assessment of children with vision impairment with the assessment of typically developing children. When assessing developmental milestones, it is important to recognize that the time when children attain specific developmental milestones will vary.

Important adaptations for children who are visually impaired

When assessing general development of children with visually impairment, it is helpful to use the examiner's observation of the child's exploration of the environment and reaction to stimuli. Doing this effectively involves structuring the testing environment to promote active exploration by the child. Such structuring might include:

- Lowering objects so they touch the body

- Adjusting the lighting for the comfort of the child

- Presenting objects in a different visual field

- Reducing background clutter

- Increasing contrast between background and test object

- Presenting objects at different distances

- Using objects with features such as sound, texture, and colored light that are of high interest to the child

- Positioning the child with appropriate support to facilitate motor activity while providing the most physical support

- Using high contrast materials
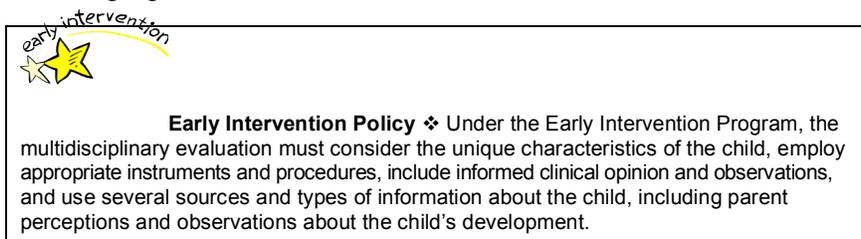
Early Intervention Policy ❖ Under the Early Intervention Program, the multidisciplinary evaluation must consider the unique characteristics of the child, employ appropriate instruments and procedures, include informed clinical opinion and observations, and use several sources and types of information about the child, including parent perceptions and observations about the child's development.

Interpreting assessment results

When interpreting the assessment results, it is important to differentiate between the scores on the test and the child's actual performance because in some cases a standard score on the test may not reflect the child's true ability. It is also important to look at how the child completes each task, the quality of the performance, and the method used. It is not enough to know only what the child is able to see and do. What the child is not able to do is also important in order to develop a baseline and design appropriate interventions.

Communicating findings to parents and other professionals

It is important for all professionals involved in the assessment to communicate with each other regarding their findings and recommendations to ensure a comprehensive assessment. It is also important that the findings of the developmental assessment be used to develop interventions for the child and family. The developmental assessment also provides useful objective reference points for monitoring the progress of the child and assessing outcomes of the interventions.

Assessment of Cognition

Cognitive development depends in part on a child's cumulative and interrelated sensory experiences. Without the full use of vision to connect the sensory input, it is more difficult for the child to perceive the totality of an object or situation that may be more readily apparent to sighted children. As a result, the very early development of cognitive skills tends to begin later in children with vision impairment.

When compared with typically developing children who have full use of their vision, children with vision impairment tend to have different patterns of development related to:

- Attention and exploration (interest in the environment is reduced due to lack of stimulation and lack of awareness of objects and events)

- General knowledge (children with vision impairment may not understand or be aware of objects with which they have no tactile experience)

- Object permanence (knowing that objects exist when they are not immediately available)

- Object constancy (recognizing similarities in objects)

- Categorization (identifying similarities and differences in objects and events)

- Spatial Relationships (understanding where objects are in relation to one another)

- Orientation (understanding where children are in relation to other people and objects in the environment)

- Cause and effect (understanding that one's actions create changes in the environment)

- Imitation (copying actions, especially those that do not produce sound such as facial expressions)

- Problem solving (conceptualizing methods to create specific changes in the environment)

Importance of assessing cognition

It is important to assess cognitive ability in children with vision impairment because it affects all other areas of development, helps determine the kinds of interventions that are most appropriate, and provides a baseline for measuring progress.

Conducting the cognitive assessment

When evaluating the cognitive function of young children with vision impairment, it is important to:

- Present items that require manipulation only after the child has had an opportunity to tactually explore the object

- Use items that have high contrast

- Avoid visual "clutter"

- Position the child for testing so that light falls on the task and not on the child's face (however, be aware of the glare factor)

- Position tasks in the child's optimal field

- Select tasks that use familiar materials because children with vision impairment may not have had exposure to as many things as other children

- Select tasks that can be easily adapted to provide tactile or auditory input

Components of the cognitive assessment

It is important that assessment of cognition in young children with vision impairment evaluate both the quantitative and qualitative aspects of a child's performance using a variety of assessment tests as available (Table 13, page 48) and appropriate observational tools and procedures, and parent interview.

It is important to remember that performance on cognitive tests may fluctuate for young children, and scores are often not stable. Therefore, cognition may not be adequately measured in a single session or single setting.

Cognitive assessment tests

Developmental assessments may be used for children with vision impairment to obtain a general assessment of development, including cognition. However, it is important to recognize that the standard scores derived from these tests are invalid because many test items require vision.

It is important to recognize that there are no norm-referenced tests designed specifically for measuring cognition in children with vision impairment.

Assessment of Sensory and Motor Development

Motor development is usually the most observable aspect of a young child's early development. Delays in motor development are often one of the early indicators of other problems such as vision impairment. Children with significant visual impairment may experience very early delays in motor development. For example, a child with significant vision impairment may have poor postural control and weak muscles due to lack of movement experiences in a variety of positions. In children with less significant impairment, delays in motor development may be more apparent later, such as delayed crawling or walking.

The majority of sensory-motor development occurs during the first year of life. If a baby with severe vision impairment is not provided vestibular, proprioceptive, and tactile stimulation, development of righting reactions and then rotation and postural tone will be delayed.

Because of reduced visual sensory input and related low postural tone, children with vision impairment may be delayed in protective reactions. Low postural tone can also limit free movement of the arms and legs, which can then interfere with the development of arm and leg extension or straightening and weight shifting. Without appropriate intervention, children with vision impairment tend to maintain immature patterns of gait because of low postural tone and incomplete sensory-motor development.

Children with vision impairment tend to progress more slowly through their developmental motor milestones and demonstrate characteristic variations in development (Table 15, page 56). However, visually impaired babies generally have the same potential to learn movement as do sighted babies. With proper identification, assessment, and intervention during the critical stages in sensory-motor development, most children can learn to compensate for their loss of vision.

The relationship between vision and motor development

It is important to understand how visual information provides sensory stimulation that encourages movement as well as providing feedback from which the child learns to correct and further develop movement. Because visual information provides the basis for activities such as reach and grasp, postural adjustment and control, and crawling and walking, it is especially important to determine whether delays in motor development are due to the visual impairment or to a neurologic or orthopedic condition.

When conducting the motor assessment, it is important to take into consideration the role that vision plays in the development of postural control, goal-directed movement, and establishing balance. It is also important to recognize how tactile, auditory, and other sensory systems may (or may not) be providing stimulation and feedback to compensate for the lack of visual stimulation.

Table 14:   Components of a Motor Assessment

Motor attributes to be assessed for all ages

- Reflexes, postural reactions, protective reactions

- Postural control

- Postural alignment and symmetry

- Muscle tone

- Muscle strength

- Range of motion and joint laxity

- Breathing (quality and effort)

- Variety and complexity of movements

- Visual attention and tracking

- Sensory responsiveness to movement and touch

- Motor milestones

When assessing the motor development of a child with visual impairment, it is important to consider the severity of the vision impairment and to assess the child's development relative to children with comparable visual impairments as well as to typically developing children.

Table 15:   Motor Milestones for Children With Severe Visual Impairment

Milestone	Age Range (in months)		Median Age (in months)	
	Sighted	**Blind**	**Sighted**	**Blind**
Elevates self by arms, prone	0.7-5	5-10	2	9
Sits alone momentarily	4-8	5-9	5	7
Rolls from back to stomach	4-10	5-10	6	7
Sits alone steadily	5-9	7-9	7	8
Raises self to sitting position	6-11	10-16	8	11
Stands up using furniture (pulls up to stand)	6-12	10-15	9	13

Table 15:	Motor Milestones for Children With Severe Visual Impairment			
	Age Range (in months)		**Median Age (in months)**	
Milestone	**Sighted**	**Blind**	**Sighted**	**Blind**
Stepping movements (walks with hands held)	6-12	8-12	9	11
Stands alone	9-16	9-16	11	13
Walks alone, 3 steps	9-17	12-19	12	15
Walks alone across room	11-14	12-21	12	19

Note: Ages rounded to nearest whole month
Adapted from: Fraiberg 1976

(Continued from previous page)

Specific assessment approaches

When assessing motor function in children with vision impairment, it is important to focus on postural reactions (such as head righting) and their development. Focusing only on motor milestones may provide a false impression that motor development is progressing normally in infants with vision impairment. It is important to include an assessment of:

- Compensatory movement strategies that may interfere with future motor development (e.g., children might use protective reactions to compensate for undeveloped postural control, or they might use neck hyperextension rather than active head control)

- The impact of muscle tone and joint laxity on the child's posture and motor control

When assessing a child's motor development, it may be useful to make some changes in the environment in order to maximize motor output (e.g., increasing or decreasing auditory and visual stimuli that may distract from or enhance motor activity).

It is important that the assessment of motor function not be limited to an evaluation of the child's progress in attaining motor milestones. It is also very important to obtain an adequate assessment of the *quality* of the movements.

Assessment of sensory processing

Since children with vision impairment will be using senses other than vision to gather information from the environment, it is important to focus on the child's typical response to environmental stimuli such as noise, movement, being touched, smells, and tastes. This is usually accomplished through parent interviews and questionnaires such as the Infant/Toddler Sensory Profile.

Assessment of Communication

Communication is the process used to produce and comprehend messages, but it involves much more than just speaking. When held, a baby can make sounds, snuggle, tense, or relax to let the parent know what is needed. As the child gets older, he or she can also look toward the caregiver and vocalize for attention, and smile in response to attention or to initiate an interaction. These interactions are the foundation of all future "conversations" and communication.

Depending on the degree of visual impairment, attempts to engage the child may or may not yield a response. The child may not know how to initiate contact in a way the parents can understand. Still, no matter how severe the visual impairment, children have ways of communicating with their parents. Parents only need to learn the child's subtle cues such as quieting in response to sound. Using touch in combination with talking is an effective component of communicating with the child because this is sensory input that the child can understand.

Children with vision impairment but no other developmental delays are likely to develop some communication skills at the same rate as sighted children. For example, development of babbling and speech sounds usually occurs at approximately the same age in both vision-impaired and typically developing children. However, other areas of development usually differ. For example, young children with vision impairment:

- Need more verbal information and descriptions of objects and events

- May not easily attach verbal labels to tactual and auditory experiences

- May stay in the echolalic (repeating words or phrases) stage longer than sighted peers

- May take longer to develop an understanding of pronouns, comparison words, and words that deal with spatial relationships and activities

Communication in young children with vision impairment involves give-and-take interaction with another person. This includes games, gestures, vocalizing, listening, speaking, singing, and even introduction to writing and/or pre-Braille.

Communication development

It is important to remember that there are many aspects to communication. Communication is more than just speaking and listening; it includes gestures and facial expressions also. Children with severe vision impairment usually need to be taught important social cues and social behaviors such as orienting the eyes toward the person speaking or being spoken to.

It is important to remember also that an infant with severe vision impairment may not initiate or respond to interactions with their parents as much as sighted children do. Some differences include:

- Smiles may be less frequent or less noticeable

- An infant may not recognize the parent's voice until the infant is touched and handled by the parent

- The child may require more time and more repetition of activities before responding

- The child may require touch cues to sustain interactions

It is important to understand that a child with vision impairment may lag in the production of words and the acquisition of vocabulary because:

- Development of vocabulary may be tied to movements and experiences so that social words and requests for specific activities or items may predominate over labels for objects

- Adults may anticipate the child's needs too well and reduce the child's need for an expanded vocabulary

- The child may rely on a limited number of rote phrases to apply to a variety of situations

Table 16:   Important Components of the Communication Assessment

Communication Skills	Pragmatics (use of language)
▪ Auditory localization ▪ Conversation skills (such as turn-taking) ▪ Imitation ▪ Listening skills ▪ Situations (where, when, and with whom does the infant communicate) ▪ Sound production ▪ Symbolic play ▪ Topics ▪ Use of gestures ▪ Vocabulary	▪ Structure/syntax (use of nouns, verbs, adjectives) ▪ Requesting ▪ Imitation ▪ Response ▪ Social devices (greetings, exclamations) ▪ Expression of wants/needs ▪ Comments on nonimmediate environment ▪ Comments on immediate environment (past, future, other places)

Assessment of Adaptive/Self-Help Skills

Self-help or self-care skills for young children generally refer to feeding or eating, dressing and managing their own clothing, and personal hygiene skills such as washing, grooming, and toileting. Young children with vision impairment often do not learn personal management skills incidentally. They may not be able to see enough to watch other family members perform routine self-care activities, model age appropriate behavior, or see themselves clearly in a mirror.

The goal for self-care instruction is independence. Lack of age appropriate self-care skills can be a source of embarrassment and frustration for the child. Although young children may not initially recognize the value of good eating skills and proper grooming, both are essential for development of self-esteem and social acceptance.

Conducting the assessment

Important strategies when conducting an assessment of adaptive/self-help skills include:

- Assessing the child's ability to demonstrate a skill in isolation as well as in a natural, functional manner

- Using the child's own clothing and personal care items before introducing unfamiliar items

- Learning from the parent the words used by the parent and child to identify body parts and describe typical daily activities

It is important to understand the cognitive level, developmental age, and motor abilities (gross and fine motor) when assessing adaptive/self-help skills.

Components of the adaptive/self-help assessment

Important components of assessing adaptive/self-help skills include:

- Eating/drinking (what kinds of foods/liquids, in what position, what utensils, with what kind of assistance)

- Dressing (clothing on and off, fasteners, manipulation of outer clothing such as a coat)

- Toileting (assisting during changing, awareness of discomfort, toilet training)

- Personal hygiene (combing/brushing hair, brushing teeth, wash/dry face/hands, bathing)

- Any compensatory skills demonstrated

- Ability to locate/replace personal possessions

- Clothing management (dresser drawers, closet, hook/peg, use of hamper)

- Ability to amuse self (how, with what, and for how long)

Assessment of Social/Emotional Development

Social/emotional development refers to the abilities to form attachments, develop a sense of self, express feelings, learn rules or expectations, and interact socially with peers and adults. It involves the ability to participate in early reciprocal interactions with parents and later, in the second year of life, with peers. The components of social development that are particularly important for young children with vision impairment include body awareness as a means of developing a sense of self, initiating and maintaining social interactions, imitation, and turn-taking.

Social interactions with young children with vision impairment may be more difficult to elicit and interpret than those with typically developing children. Children with vision impairment tend to have a more limited repertoire of facial expressions and to be less responsive than sighted children. The lack of visual perception also appears to delay the acquisition of the concept of carrying on a dialogue.

The degree to which a child's social skills may be limited depends, in part, on the severity of the visual impairment. Some children will have enough vision to observe and imitate the facial expressions of others, and some children will not.

Importance of assessing social interactions and relationships

It is important to take into account the developmental characteristics of young children with vision impairment when assessing social development. For example, young children with vision impairment often:

- Smile more in response to tactile stimulation
- Have decreased or absent eye contact, gaze, or smiling as typical ways of responding to, initiating, and maintaining contact with the parent
- Respond in unexpected or misunderstood ways (e.g., quieting when interested in an activity or listening to the parent's voice rather than showing increased excitement and activity as sighted infants do)
- Have a restricted repertoire of facial expressions
- Demonstrate separation anxiety at a later age than sighted children do since object permanence develops later in visually impaired children
- Demonstrate avoidance reactions to strangers only when the stranger touches or attempts to pick up the child and not in response to a stranger's voice
- Are less responsive to games that involve objects (ball play) than are sighted peers
- Fail to initiate social interactions

Components of the assessment

Important components of assessing social interactions and relationships include assessment of:

- Sense of autonomy
- Social initiation

- Social imitation

- Ability to self-comfort (how/with what)

- Self-stimulatory behaviors (what type, when it occurs, for how long)

- The child's attachment behavior patterns in the presence of the parent

- Age expected reciprocity (dialogue, turn-taking during play)

- Social interactions with familiar as well as unfamiliar adults and peers

- The child's ability to make transitions from one play activity to another

- Joint attention (shared interest in object or activity)

ASSESSING ORIENTATION AND MOBILITY

When a child has significant early vision loss, it is recommended that formal orientation and mobility (O&M) assessments begin when the child is approximately 6 months old.

Orientation is the process of utilizing sensory information to establish and maintain one's position in the environment.

Mobility is the process of moving safely, efficiently, and gracefully within one's environment

The purpose of orientation and mobility assessment is to identify the strengths and needs of the child and family with the goal of developing strategies that will promote the child's abilities to travel in any environment as independently as possible. Important orientation and mobility concepts to assess (depending on the child's age) include:

- Sensory awareness

- Awareness of environment

- Basic protective/information-gathering techniques

- Gross and fine motor skills

- Spatial concepts and relationships

- Orientation skills

- Use of residual vision for mobility

- Body image (the ability to name body parts, move them purposefully, and understand how body parts are connected
- Laterality (understanding one's own right and left side, and integration of right-side/left-side)

General approach for O&M assessments

It is recommended that monitoring of orientation and mobility needs to be included as a component of the ongoing assessment process for all young children with vision impairment, regardless of amount of residual vision. Formal orientation and mobility assessment is recommended when a specific orientation and mobility need is identified such as:

- The child demonstrates a desire to travel independently but needs assistance to do so safely
- The child demonstrates marked reluctance to move independently
- The child has difficulty developing independent movement skills
- The child demonstrates unsafe independent travel skills, such as not stopping at the top of stairs
- The family or other team members request an evaluation
- A child with vision impairment falls four months behind on gross motor developmental milestones, and the delay cannot be attributed to a motor disorder, such as cerebral palsy

Components of an O&M assessment

Important components of an O&M assessment include:

- Information on the eye condition and on functional implications of that type of vision loss
- Any important health/developmental/background information that may impact the child's development
- How the child uses vision (indoor, outdoor, familiar and unfamiliar areas)
- Ability to generalize and use the skill in a normal, functional manner
- Basic concept development including awareness of body parts, positional concepts, and spatial concepts (as appropriate for the child's developmental age)
- Amount of residual vision

- Basic auditory functioning
- Basic gross motor functioning
- Ability to use tactile cues
- Any compensatory skills demonstrated
- Amount and type of independent travel, amount and type of guided travel
- Any concerns raised by the child's parents or other professionals working with the child

ASSESSING THE NEED FOR ASSISTIVE TECHNOLOGY DEVICES

There are a variety of assistive technology (AT) devices that can help children with vision impairment participate in daily life activities. The goal of AT should be for the child to be able to function at a higher level of efficiency with the AT device than without it.

Assistive technology devices can be either low technology or high technology. High-technology devices typically have greater complexity and may include an electronic component. Assistive technology services support the use of the devices in the child's natural environment. Any member of the child's team can recommend an AT assessment for a child with vision impairment.

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early intervention

Early Intervention Policy ❖ Assistive technology devices may be provided to children eligible for the Early Intervention Program when these devices are necessary to increase, maintain, or improve the functional capabilities in one or more of the following areas of development: cognitive, physical (including vision and hearing), social/emotional, communication, or adaptive development.

Components of the AT assessment process

In determining which specific AT devices are appropriate for a child, it is important to begin with information about the current needs of the individual child and family, including:

- The child's visual functioning

- The specific needs and preferences of the child and family

- The child's cognitive, motor, and language capabilities

- The potential for improving the child's function

- The family's past experience with and willingness to use AT

- Other AT devices/equipment currently being used

Selecting AT devices

It is important that any AT being considered have purpose and meaning for both the child and the parent. It must be practical and feasible for the family to use. If a child's vision can be corrected with an AT device, the professional should encourage the parents and train them in helping their child use it. Assistive technology provides no benefit if it is not used.

When considering options for AT devices, it is important to identify options that can help the child achieve the highest level of independence. Acceptable low-tech options, if available, often allow the child to develop more independent function.

Table 17:   Questions to Ask When Evaluating Assistive Technology

Social
- Will the device enable the child to participate in activities with greater independence?
- Is the device a "normal" piece of equipment used also by nondisabled children?
- Is the device age-appropriate?
- Will family members support the child's use of the device?

Motor
- Are the child's motor capabilities compatible with the device?
- Will the device enhance motor development?
- Are there any potential long-term negative effects on motor and physical development from using the device?

Vision
- Are there any potential vision-related disadvantages of the device?
- Are there other devices that might meet both vision and motor needs?

Safety
- Is the device safely constructed for the intended purpose?
- Is the child able to and will the child use the device in a manner safe to self and others?
- Have limitations been established to assure safe use?

Table 17:   Questions to Ask When Evaluating Assistive Technology

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Adaptability
- Can the device be custom fitted to the child?
- Is the device modifiable to change with the child's needs?

Training
- Are trained professionals familiar with the device available to provide instruction and monitor use of the device?
- Can parents and others be trained to appropriately monitor use of the device?

Travel/Portability
- Is the device appropriate for the distances that the child will usually be traveling and for the locations?
- Will the device make travel more efficient?

Cost
- Is the device affordable to the family OR is there an alternative payment source?
- Have less expensive alternatives to the device been explored?
- Do the potential benefits of the device outweigh the costs?

Maintenance
- Is the device durable enough to withstand the purposed use?
- Is the device easy to repair locally?

Availability
- Can the device be easily obtained?
- Can the device be obtained locally?

Adapted from: Clarke 1988
(Continued from previous page)

Professionals conducting the AT assessment

It is essential that the professionals assessing the need for AT:

- Be knowledgeable about AT and as the specific device(s) being considered

- Consult with the other service providers and family

- Understand (and ensure parents understand) that these devices may be temporary and that their immediate benefit is to assist with the child's interaction with the environment and the accomplishment of new skills

- Consider the need for AT services (training and customization) to support the use of any devices that might be recommended

WORKING WITH THE FAMILY

Informing the Family About the Diagnosis

When there is an indication that a child may be visually impaired, it is important to inform the family in a sensitive and caring way.

Informing the parents of an infant's potential for a disability

As soon as there are indications that a child either may have or be at significant risk for vision impairment, it is important for the physician to communicate this to the parents and make a referral to an appropriate ophthalmologist or optometrist.

It is important to provide all parents and other primary caregivers of young children who have or are at risk for vision impairment accurate information about their child's condition in order to allow them to:

- Function as active partners with health care providers in monitoring the overall development and health of their child

- Have informed and reasonable expectations for their child's development

- Become informed advocates for their child

Conveying the news about a child's diagnosis or risk for disability

When a young child is either at high risk for or is suspected of having vision impairment, it is recommended that the physician share this information with the parents in person and that every effort be made to convey the news in private rather than in the presence of strangers. Parents should be given the opportunity to have additional support present if they wish. It is also important for the physician to recognize that:

- Parents need to be able to hope and believe in a positive future for their child

- It is unlikely to know with certainty the prognosis of serious medical complications during the neonatal period

- Many parents are able to accept uncertainty, and it is important for physicians to provide an honest assessment of the range of potential outcomes for their child

It is important to recognize that parents' understanding of what a diagnosis means for their child's future and for family life may be based on stereotypes and misinformation. Parents may be concerned that the diagnosis implies their child will never see, never function independently, and always have to attend a special school. Therefore, it may be important to discuss not only what a diagnosis means but also what it does not mean.

When a young child is at high risk for or is suspected of having vision impairment, it is important to include specialists with expertise in the care and follow-up of young children with vision impairment (ophthalmologist, optometrist) as part of the team available to discuss the health and developmental implications of the child's condition.

Communicating with the family

When communicating with the family about a child's disability or risk for a disability, it is important for health care professionals to:

- Be respectful and provide understandable information

- Listen to and consider parents' observations of the child

- Focus on and appreciate the child as a valuable person, an individual, and a member of the family, avoiding negative terms or language relating to the condition or the child

- Make reference to and consider the child's specific personal qualities (e.g., the child's determination or happy temperament) and positive individual attributes, strengths, and characteristics

Professionals need to be aware that even if the news is conveyed in the best possible way, parents may still express anger or dissatisfaction when informed that their child has significant vision impairment. It is important that professionals listen to the reactions of family members so that appropriate support and information can be provided. It is also important to understand that not all families will have the same reaction.

It is important to understand that adjusting to the diagnosis may take time, and as family members go through various phases of understanding and acceptance, their need for information and support may increase.

When informing parents that their child may have a vision impairment, it is important to recognize that parents of children with disabilities often hold themselves accountable or feel others hold them accountable for their child's disability. It is important to provide information to the parents about the cause of the vision impairment and inform the parents that it is not the result of something they did or did not do (if this is, in fact, accurate).

It is important for professionals to recognize that parents have a range of individual responses and emotional reactions to the experience of having a child who may have serious medical problems and the potential for disabilities. When interacting with parents, it is important for professionals to:

- Be accepting and avoid being judgmental toward the parents

- Pay attention to and value the parents' opinions and feelings

- Recognize that parents are valuable observers who have knowledge about the child that needs to be considered when planning their child's care

- Provide opportunities for the parents to voice their concerns and emotions

- Ensure that parents know about and are offered opportunities for professional support such as counseling and emotional support

Assessing the Resources, Priorities, and Concerns of the Family

The family assessment

A family assessment is designed to help identify the family's resources, priorities, and concerns so that intervention plans that are meaningful and relevant to the family can be developed. This is an important component of planning interventions that will benefit the child and family.

The resources, priorities, and concerns of the family may be more predictive of outcome than the child's needs are, both for parent-related outcomes and child outcomes. Therefore, intervention services are most effective if they are matched to the specific needs of the family.

Early Intervention Policy ❖ A family assessment must be offered as part of the multidisciplinary evaluation for the Early Intervention Program. Family participation is optional.

It is important to recognize that family strengths and needs may change over time. Because family resources, priorities, and concerns may change over time, ongoing family assessment is an important component of the intervention plan.

Family assessment methods include:

- Informal discussions with families, using sensitive and focused interviewing techniques
- Questionnaires and other assessment tools to help families identify, clarify, and communicate their goals and needs to relevant professionals

Components of a family assessment

It is recommended that assessment of the resources, priorities, and concerns of the family include observation and/or discussion of factors such as:

- The family's knowledge and need for information about vision impairments
- The family's future expectations for the child, both short- and long-term
- Family composition (siblings and extended family)
- Family demographics, education, and family specific circumstances
- Family values and culture
- The family's stressors and tolerance for stress, as well as the family's coping mechanisms and styles
- The family's current support systems and resources (including extended family members and their attitudes)
- Family interaction and patterns of parenting style
- Caregiving skills and sharing of family caregiving responsibilities
- Interpersonal and problem-solving styles
- Issues related to nonsupportive behaviors of family members, friends, and community

Considering the cultural and family context

A child's life is embedded within a cultural and family context. It is essential to consider the family's culture, parent priorities, parenting styles, and family support systems. It is also important to recognize that the cultural and familial differences may shape the family's expectations about play and social

interaction, pragmatic use of language, and eye contact and the development of adaptive or self-help skills and independence.

In assessing the family's resources, priorities, and concerns, it is important to recognize the role of the family's cultural and ethnic background and how it may affect:

▪ Who within the family serves as the primary decision maker regarding the child

▪ Styles of interaction within the family and between the family and others

▪ Integration of the nuclear family within larger networks, including extended family and community groups

▪ Access to/ease in using different types of information

▪ The family's comfort with openly expressing needs

Family assessment approaches

Because some families may be uncomfortable about participating in a family assessment, it is important for professionals to:

▪ Establish a collaborative relationship with the parents

▪ Listen effectively and nonjudgmentally

▪ Maintain confidentiality

▪ Provide an appropriate setting and sufficient time to allow family members to express their needs and concerns

▪ Respect differences in family styles and goals

▪ Respect cultural differences

▪ Avoid tendencies to judge the family's adequacy

To measure the impact of parental stress on family well-being and child functioning, it may be useful to use a specific measurement tool such as the Parenting Stress Index, the Coping Inventory, or the Family Resource Scale.

CHAPTER IV: INTERVENTION

There is no single intervention approach that will be appropriate for all children with vision impairment. Any intervention plan for a child with vision impairment needs to be individualized to the child's specific type of vision impairment, the specific needs of the child, and the resources, priorities, and concerns of the family.

The needs of the child and the family will determine the type and frequency of the intervention as well as the appropriate time to initiate the intervention. Some children will be identified soon after birth and may enter into an intervention program at a very young age. Some children may have early indicators of a potential problem that require ongoing monitoring before the need for intervention is determined. Other children will not be identified until later. Some children may benefit from treatment (surgery, glasses) that will correct or improve the child's visual abilities; other children may not benefit.

Importance of early identification and intervention

It is important to identify children with vision impairment and begin appropriate intervention as soon as possible because early identification and appropriate intervention may help accelerate the child's overall development and lead to better long-term functional outcomes.

Early Intervention Policy ❖ Children's eligibility under the Early Intervention Program can be established through the presence of either a developmental delay that meets the state definition of developmental delay or a diagnosed condition that has a high probability of resulting in developmental delay. An approved multidisciplinary team selected by the parent must establish a child's eligibility for the program.

GENERAL CONSIDERATIONS FOR PLANNING AND IMPLEMENTING INTERVENTIONS

Developing the overall intervention plan

A comprehensive model of intervention strategies that includes opportunities for home- and/or community- or center-based services as well as family support services is recommended for most young children with vision impairment. It is important to develop strategies specific to the needs of the child and family.

It is important that the overall intervention plan for the child be developed with participation of both professionals and parents, and that this plan:

- Define desired outcomes and identify objective criteria for measuring them

- Ensure all individual intervention components are compatible and coordinated to avoid any potential conflicts

- Provide for baseline and ongoing assessment of the child's progress, and specify the methods, schedule, and criteria for such periodic assessments

- Provide for appropriate modification or discontinuation of the intervention based on periodic assessment of the child's progress

> **Early Intervention Policy** ❖ When children are found to be eligible for the Early Intervention Program in New York State, an Individualized Family Service Plan (IFSP) must be in place within 45 days of referral to the Early Intervention Official. The IFSP must include a statement of the major outcomes expected for the child and family, and the services needed by the child and family. Services included in the IFSP are provided at no cost to parents (see Appendix B).

Determining the intervention setting

In determining the most appropriate intervention setting, it is important to consider:

- The range of the child's natural environments (home, child care provider, community settings) and how these settings can support the intervention objectives

- The appropriateness of the setting for supporting the needs of the family and child

- The child's ability to use vision to function in various settings

- Ability to modify the setting to adapt to the needs of the child

- The child's cognitive, social, communication, and motor development

- The child's health status and associated health conditions

Early Intervention Policy ❖ Early intervention services can be delivered in a wide variety of home- and community-based settings. Services can be provided to an individual child, to a child and parent or other family member or caregiver, to parents and children in groups, and to groups of eligible children. These groups can include typically developing peers. Family support groups are also available.

Under federal and state laws and regulations, early intervention services must be provided in natural environments to the maximum extent appropriate to meet the needs of the child and family. Natural environments are settings that are normal for the child's same-age peers who have no disabilities.

Selecting intervention strategies and targets

In making a decision to start or change a specific intervention for a child with vision impairment, it is important that parents and professionals consider:

- The best scientific evidence about the intervention

- The effectiveness of the intervention and available alternatives for the child and family

- The child's developmental needs and skills

- Current needs based on context and environment

- The family's resources, priorities, and concerns

- Potential risks and costs associated with the intervention

When planning intervention strategies, it is important to consider the child's functional visual skills (the ways the child uses vision) and to plan for interventions within the context of daily routines such as mealtime and play activities. The steps in this process include:

- Determining the type of intervention based on the needs of the child and family

- Identifying specific visual behaviors, e.g., tracking, responding to facial expressions

- Developing an intervention plan that includes specific techniques to support participation in routine activities in the child's environment

Determining the frequency and intensity of the intervention

When determining the frequency and intensity for interventions, it is important to consider the child's and family's needs, routines and schedules, the child's ability to engage in and tolerate the intervention, the intervention setting, and the balance of the intervention with the child's and family's routines and schedules.

Considering the child's health status

Before initiating interventions for a young child with vision impairment, it is important to consult with the child's primary health care physician to ensure that there are no contraindications.
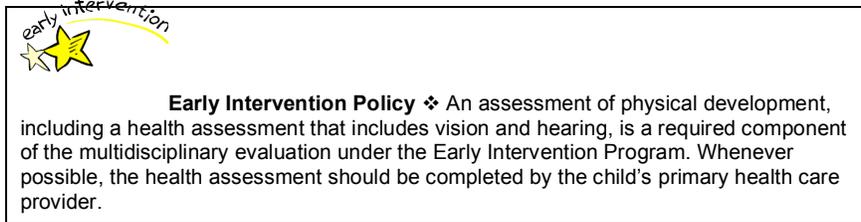
Early Intervention Policy ❖ An assessment of physical development, including a health assessment that includes vision and hearing, is a required component of the multidisciplinary evaluation under the Early Intervention Program. Whenever possible, the health assessment should be completed by the child's primary health care provider.

Ongoing monitoring of progress and modification of the intervention plan

It is recommended that any intervention be tied to ongoing assessment and modification of intervention strategies as needed. It is recommended that parents and professionals consider modification of an intervention when:

- The child has progressed, and target objectives have been achieved

- Progress is not observed after an appropriate trial period

- The child has shown some progress but target objectives have not been achieved after an appropriate trial period

- The child's behavior or health status unexpectedly changes

- The intervention setting changes

- Family priorities change

In addition to ongoing monitoring, it is recommended that periodic reassessment of the child's progress and overall developmental status be conducted at least once every six to twelve months. During the reassessment it is important to:

- Include appropriate qualitative information about the child's development and progress

- Include both qualitative information and appropriate standardized testing of the child's progress using an outcome measure that is responsive to change

- Assess the child's individual progress and functional level and then compare these to the child's age-expected levels of development and functioning

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Early Intervention Policy ❖ The Individualized Family Service Plan (IFSP) must be reviewed every six months and evaluated every twelve months. The IFSP may be amended any time the parent(s) and the Early Intervention Official (EIO) agree that a change is needed to better meet the needs of the child and family. These amendments may be based on ongoing assessments and/or an evaluation of the child's developmental status.

Supplemental evaluations may be conducted as recommended by the IFSP team if agreed to by the parent and EIO, and included in the IFSP.

In the Early Intervention Program, the IFSP must be in writing and have required components specified in program regulations.

Evaluating the child's progress and effectiveness of the interventions

When assessing the child's progress, it is important to consider:

- Objective tests of the child's development (Table 13, page 48)

- Direct observation of the child's developmental/functional skills by a professional with experience in the area of vision impairment

- General impressions from parents and other professionals working with the child regarding the child's developmental progress and adaptive independent functioning

When evaluating the effectiveness of interventions over time and deciding whether specific interventions are effective or whether the intervention plan needs to be modified, it is important to consider the following:

- When children are receiving multiple interventions at the same time, it is difficult to assess the effectiveness of any individual therapy

- In evaluating the usefulness of interventions for children with vision impairment, it is important to evaluate the child's progress in all developmental areas

- Because of normal developmental maturation, the overall functional level of many children with vision impairment will generally improve over time regardless of what intervention they receive (or even if no interventions are provided)

Collaboration, coordination, and integration

It is important for all team members, including the parents, service providers, and the child's health care provider, to find ways to communicate consistently and regularly with each other about the child's progress.

Qualifications and experience of professionals providing interventions

It is essential that all professionals providing and supervising interventions for young children with vision impairment:

- Have experience working with young children with vision impairment and have specific training for the intervention method

- Understand the developmental patterns commonly associated with vision impairments in young children and the related implications for intervention

- Have skills in promoting and supporting the participation of parents as team members within the context of the family's resources, priorities, and concerns

General Approach for Evaluating Intervention Options

It is important to recognize that parents may seek out and receive information about a variety of intervention approaches from multiple sources. Because information about some interventions may be limited or incorrect, it is important to evaluate the accuracy of such information, rather than taking effectiveness claims at face value. It is also important to understand that some interventions may not have established efficacy for improving the child's vision or functional skills, but may still benefit the child if the interventions provide physical activity, opportunities for social interaction, or otherwise facilitate the child's overall development. Table 18 and Table 19 (pages 80-81) suggest questions to consider when evaluating various interventions and intervention service providers.

When evaluating information about the effectiveness of interventions, it is important to understand that:

- The best way to assess the effectiveness of interventions is to rely on the results of controlled research trials and other well-designed research studies that attempt to control for placebo and maturation effects, the natural history of the condition, and other potentially confounding factors

- Results of uncontrolled studies and individual reports about the effectiveness of intervention methods can be misleading because they often do not adequately control for factors that might bias the study results

- Results may vary for individual children regardless of study results

- There is a difference between clinical significance and statistical significance when interpreting research findings

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Table 18:   Questions to Ask When Selecting Interventions

- What do we want to accomplish from this intervention? Is the intervention likely to accomplish this?

- Are there any potentially harmful consequences or side effects associated with this intervention?

- What positive effects of the intervention would we hope to see?

- Has the intervention been validated scientifically with carefully designed research studies in young children with vision impairment?

- Can this intervention be integrated into the child's current program?

- What is the time commitment? Is it realistic?

- What are the pros and cons of this intervention? What are professionals' and other parents' opinions?

- What claims do proponents make about this intervention? (Note: Claims of dramatic improvement are probably a "red flag.")

- Does the provider of the intervention have knowledge about the medical and developmental issues associated with vision impairments?

- Does the provider of the intervention have experience working with young children with vision impairment?

- What do the child's pediatrician and other professionals who know the child think about the intervention's appropriateness?

Adapted from: Nickel 1996

Table 19:   Questions to Ask When Selecting Intervention Service Providers

- What kinds of intervention, therapy, and services are available through this provider?
- Does the intervention provider have a particular philosophy for working with children with vision impairment?
- How many hours per week do these services require?
- How are the interventions structured (one-on-one time with the child, peer groups, parent-child instruction)?
- In what kind of setting(s) is the intervention provided (home, office, clinic, group setting with peers)?
- What occurs in a typical intervention session?
- What experience do the teachers and/or therapists have working with children with vision impairment?
- What experience do the teachers and/or therapists have working with children who have other disabilities in addition to vision impairment?
- What experience does the program supervisor have?
- How closely does the program supervisor work with the therapists, teachers, and parents?
- What are the requirements for ongoing training for staff? What opportunities for ongoing training are offered to the staff?
- Are parents involved with planning as part of the intervention team?
- Is there a parent education/parent training program?
- How much and what kinds of involvement are expected of parents and family members?
- Are parents welcome to participate in or observe intervention sessions?
- Are there opportunities for integration with sighted children?
- How is the child's progress evaluated and how often?
- How are parents informed of the child's progress?

Including the Family in Planning and Implementing Interventions

The child's needs are best understood within the context of the family and the family's culture. Therefore, intervention services are most effective when matched to the child's strengths and needs as well as to the family's resources, priorities, and concerns (see page 70).

It is possible that the intervention process will begin very early for many families because children with vision impairment can often be identified during the first year of life. Therefore, many of the interventions focus on the parents rather than the infant and provide parents with information about vision impairment, ongoing monitoring and vision surveillance, or the need for family support. Even when a professional is working directly with the child, informal or formal parent training may be an important component of the intervention.

Importance of parent involvement

Parent involvement can be critical to the success of an intervention. It is important that parents be involved in the assessment and intervention for their child in order to understand:

- What to expect regarding their child's vision and general development

- Intervention options, goals, methods, and evaluative progress

- How to use naturally occurring opportunities to support and integrate treatment objectives into the child's care at home

- How to advocate for their child

Level of parental involvement

It is important for parents to participate in the intervention planning process and in supporting and implementing interventions. It is recommended that decisions about the extent of parental involvement in interventions take into account the parents' level of interest, availability, and ability to participate in the intervention. It is also important to consider the availability of training and professional support. A home program carried out by parents under the direction of a qualified professional can be an important part of the overall intervention.

Considering the cultural context of the child and family

It is important to remember that family members' beliefs and values may affect many different aspects of the relationship with their child as well as their relationships with professionals (Table 20, page 83).

Early Intervention Policy ❖ Providers and Early Intervention Officials must make reasonable efforts to ensure that an individualized approach is used in delivering services to children and their families, including consideration and respect for culture, lifestyle, ethnicity, and other family characteristics.

It is essential to consider and respect the family's culture and primary language when providing interventions for young children with vision impairment. It is recommended that interventions be provided in the primary language of the child and family whenever possible. It is also recommended that the professional consult with someone familiar with the family's culture and language if necessary, and that if an interpreter assists in the intervention, he or she be trained to provide culturally and linguistically accurate interpretations.

Table 20:   Influence of Family Beliefs and Values: Considering the Cultural Context of the Family

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The cultural context of the family may influence the following aspects of planning and implementing interventions:

- Expectations regarding the child's development

- Expectations and desires regarding developing a child's independence

- Parents' confidence in working with a child with special needs

- Patterns of caregiving responsibilities within the family

- The level of privacy desired within the home (and thus the decision of the home versus other potential settings for the intervention)

- Use of space in the home

- Patterns of feeding and holding a young child

- The child's preferred sleeping patterns

- Use of traditional or alternative treatments and therapies

- The family's health practices

- Comfort with having the child present in public places

- Parents' level of comfort with interacting with professionals

Working with parents

It is recommended that professionals work collaboratively with parents in all stages of the intervention program, elicit observations from the parents regarding the child's functioning, and share regular progress reports with the parents.
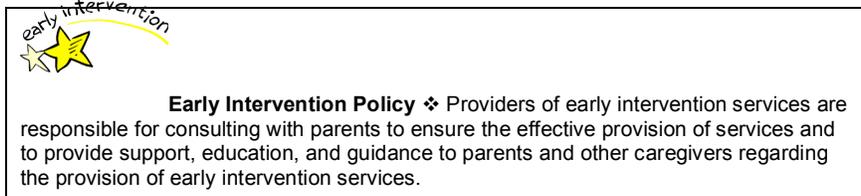
Early Intervention Policy ❖ Providers of early intervention services are responsible for consulting with parents to ensure the effective provision of services and to provide support, education, and guidance to parents and other caregivers regarding the provision of early intervention services.

It is important for professionals to provide instructions/education to parents that will help them foster their child's development in all domains. Teaching methods include verbal instruction, written material, supervision, videotapes, hands-on training, and participation in intervention sessions.

Parent education and training

When intervention options are being considered, it is important to provide parents with information about:

- Intervention options that are appropriate and available for their child

- The types and effectiveness of the various interventions that may be available

- The types of professionals who may be providing interventions and what they will be doing

When an intervention plan is developed, it is recommended that structured parent education, including appropriate parent training, be part of any intervention program.

It is important that parent education and training includes instructing parents about specific techniques focused on providing opportunities for increasing the child's personal independence and functioning as a part of the family.

Other important components of parent education and training programs include:

- Teaching appropriate play activities that integrate the objectives of the intervention into the child's daily life activities

- Helping parents determine strategies for teaching and reinforcing routines that take place throughout the day
- Helping parents understand the child's approach to learning
- Providing support and education through parent-infant interaction groups
- Modeling, demonstration, manual guidance, and verbal feedback

Providing Support to Parents and Families

Family support refers to informal and formal support and can be planned or can occur naturally. Informal support is often characterized by psychological closeness and mutual caring that enhances competence and feelings of well-being. Informal family support is usually intended to support the parents, but it may also have indirect influences on child outcomes.

Family support generally has the following five components:

- *Relational* – the existence and quantity of social relationships
- *Structural* – quantitative aspects of personal social networks
- *Functional* – the type, quantity, and quality of help provided
- *Constitutional* – the extent to which the support offered matches the indicated need for help
- *Support satisfaction* – the extent to which support is perceived as helpful

It is recommended that formal family support plans be developed in conjunction with the family to ensure that they match family needs. Not all families need the same level of support. When providing support to families, it may be useful to consider ways of helping the family to mobilize informal support networks rather than relying only on formal support.

It is important to establish a collaborative parent-professional relationship in which the professionals are able to listen effectively and nonjudgmentally to family-identified needs.

If professional support is provided, it is recommended that this support be provided in response to an indicated need for particular kinds of information or resources and in a way that mirrors features found in the family's informal support networks.

It is important to recognize that family support is not a panacea but is one of many intrapersonal, interpersonal, and environmental factors affecting the functioning of children and their families.

MEDICAL AND SURGICAL INTERVENTIONS TO IMPROVE VISION

> **Early Intervention Policy** ❖ The Early Intervention Program does not cover the costs of medical interventions, surgical procedures, or primary health care services that are needed by any child in the program.

General Considerations for Medical and Surgical Interventions

During infancy and early childhood, there is a unique opportunity to influence the child's visual system because the brain and the visual system are still developing. The number of neural cells, maturation of neuronal elements, and the growth of neural networks continue to increase in the early childhood years. Because the development of the visual system can still be influenced by the quality and level of visual input received when the child is very young, early identification of and intervention with young children with vision impairment is especially important.

General considerations for medical/surgical interventions

It is important to remember that there are many causes of vision impairment and some of these may be improved with medical treatment while others may not. A number of vision problems (e.g., congenital cataracts) can be identified at birth. It is important for professionals to identify and adequately evaluate these conditions as early as possible because in most cases, early treatment is likely to improve the visual outcome.

Some conditions resulting in vision impairment, such as corneal opacities and cataracts, may be apparent at an early age and are generally correctable with medical and surgical intervention. Other conditions, such as foveal hypoplasia, optic nerve hypoplasia, and optic nerve coloboma, are not correctable with medical or surgical intervention. It is important to remember that some children may have more than one condition causing their vision impairment.

To promote the development of good vision, it is important to remove significant obstructions along the visual axis and to provide appropriate optical correction as needed. Conditions that may obstruct the visual axis include cataracts, ptosis (a drooping eyelid) when it occludes the pupil, corneal opacity, and vitreous hemorrhage.

It is important to understand that the earlier the onset of a visual impairment, the longer the duration of the visual impairment, and the greater the level of visual deprivation, the poorer the response will be to any treatment to improve vision.

When making decisions about medical and surgical interventions, it is important to weigh the potential benefits and the likelihood of good outcomes against the potential risks.

Table 21:   Examples of Medical and Surgical Interventions

Conditions that may result in low vision in young children

Condition Affecting Vision	Medical/Surgical Treatment
Albinism	
Lack of pigmentation of the eyes resulting in nystagmus, photophobia, and reduced visual acuity	Tinted lenses may be needed for eye comfort because of light sensitivity (photophobia)
Amblyopia	
Decreased visual acuity due to lack of a clear image falling on the retina; almost always unilateral	Good eye usually patched to stimulate the brain cells associated with the affected eye
Cataract	
Opacity (a cloudiness) of the lens, of the eye or its capsule, or both	Usually needs to be surgically removed; dilation may be an option for small cataracts
Cortical visual impairment	
Reduced vision due to cortical damage in one or more areas of the brain; frequently associated with other neurological problems	No medical/surgical treatment available
Glaucoma	
Increased pressure in the eye (intraocular pressure)	Usually requires surgery; eye drops may also be needed
Nystagmus	
Constant, involuntary, cyclical movement of the eyeball	Usually not treated; occasionally surgery may be performed
Optic nerve dysplasia	
Abnormality of optic nerve development	No medical/surgical treatment currently available

Table 21:   Examples of Medical and Surgical Interventions

Conditions that may result in low vision in young children

Condition Affecting Vision	Medical/Surgical Treatment
Optic nerve hypoplasia	
Small, underdeveloped optic nerve	No medical/surgical treatment currently available
Retinal detachment	
Separation of the retina from the supporting structures in the eye	Surgery, cryotherapy, laser therapy, or intraocular surgery
Retinoblastoma	
A malignant tumor of the retina	Surgery, radiation and/or chemotherapy
Retinopathy of prematurity (ROP)	
Abnormal development of the retina due to growth of blood vessels into the retina	Laser therapy or cryotherapy; retino-vitreal surgery may be needed for advanced cases
Strabismus	
Ocular misalignment, squint	Surgery, orthoptics, corrective lenses (glasses)

(Continued from previous page)

Cataracts

A thorough evaluation of cataracts in young children is important to make decisions about the need for treatment. Not all cataracts need to be removed. Important factors to consider when making treatment decisions include:

- Size, shape, and position of the cataracts

- Optical density of the cataract

- Bilerallity of cataracts

- Tendency for progression (including family history)

- Prenatal history

- Coexisting ocular abnormalities

It is important to understand that without appropriate optical and visual rehabilitation, the prognosis following cataract surgery is poor. Methods to visually rehabilitate a child after removal of a cataract include contact lenses, glasses, intraocular lenses (IOL), and treatment for amblyopia (often secondary to cataract).

Contact lenses are generally recommended in preference to glasses for young children after cataract surgery because contact lenses often produce a more natural image, wider visual field, and less distortion. In these situations, contact lenses are not considered a cosmetic appliance but are medically indicated. Although IOL are typically used as the optical correction for cataract surgery in adults, IOL are not typically used after cataract surgery in children because IOL have not been shown to produce better visual outcomes than glasses or contact lenses.
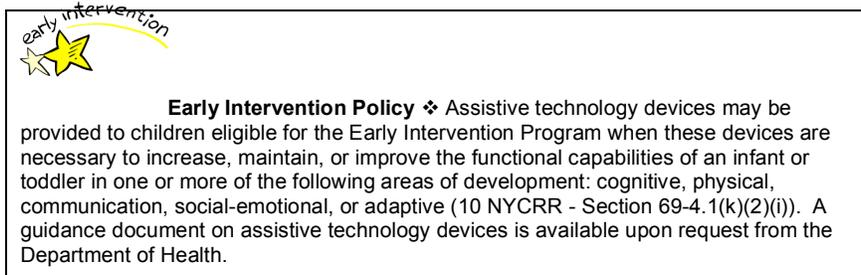
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early intervention

Early Intervention Policy ❖ Assistive technology devices may be provided to children eligible for the Early Intervention Program when these devices are necessary to increase, maintain, or improve the functional capabilities of an infant or toddler in one or more of the following areas of development: cognitive, physical, communication, social-emotional, or adaptive (10 NYCRR - Section 69-4.1(k)(2)(i)). A guidance document on assistive technology devices is available upon request from the Department of Health.

Corneal opacities

It is important to understand that corneal transplants may be an option for children with significant visual obstruction due to corneal opacities. However, full thickness corneal transplants (penetrating keratoplasty) are controversial for children who are under 3 years of age, particularly when the corneal opacity is only on one eye. Results of full-thickness corneal transplants in infants tend to be poor, and complications are frequent and may result in other problems.

Cortical visual impairment and optic atrophy

Cortical visual impairment results from damage in one or more areas of the brain and is frequently associated with other neurological problems. There are currently no medical or surgical treatments that can improve vision for children with significant optic atrophy, optic nerve hypoplasia, or cortical visual impairment. However, it is important to treat any underlying medical causes for these conditions.

Glaucoma

It is important to recognize that early diagnosis of glaucoma may be difficult in young children. Infant glaucoma (unlike adult glaucoma) generally requires surgical intervention. Multiple surgeries and frequent examinations under anesthesia may be necessary. Eye drops may also be used to treat glaucoma in young children, and it is important for parents to be aware of the systemic effects that may occur in young children.

Vitreo-retinal problems/Retinopathy of Prematurity (ROP)

It is important to recognize that if a young child has significant ROP, appropriate treatments may improve the visual outcome. For infants at high risk for retinopathy of prematurity (ROP), ongoing medical surveillance, both in the neonatal nursery and after discharge, is crucial. It is important to continue monitoring the vision of low birth weight premature infants until the retina is fully vascularized (determined by ophthalmoscopy).

It is important to recognize that if a young child has significant ROP, appropriate treatments may improve the visual outcome. Treatments that are sometimes used for ROP include laser therapy, cryotherapy, and in the most advanced cases of ROP, retino-vitreal surgery.

Vitreo-retinal problems/retinitis pigmentosa (RP)

It is important to recognize that RP is a degenerative retinal condition that causes a decrease in vision. Functional visual problems from this condition seldom occur in children younger than 10 years old. Currently, there is no known effective treatment for this condition. If a child is at risk for certain types of retinitis pigmentosa based on family history or eye exam findings, it is recommended that tests be conducted to establish the diagnosis. Certain types of RP can be diagnosed in children under 3 years of age with electrophysiological testing.

Evaluation and genetic counseling are recommended for children with retinitis pigmentosa because:

- Genetic testing can help determine the specific type of RP, and knowing the specific type of RP has implications for understanding prognosis and making decisions about interventions

- Genetic counseling may help parents understand the availability of prenatal diagnosis and risk of occurrence in siblings

It is recommended that young children diagnosed with retinitis pigmentosa have appropriate referrals for assessments to identify associated conditions such as deafness, motor delay, mental retardation, and other neurological abnormalities.

Craniofacial anomalies

It is important that children with craniofacial anomalies always have an early comprehensive medical evaluation because they frequently have multiple medical problems. They should have a comprehensive visual assessment also because they frequently have vision problems.

Optical Correction

The most common vision impairments are due to refractive errors. Refraction refers to the way in which light rays are bent when passing through the eye before falling on the retina. Normal vision requires that the rays focus on the retina as illustrated below. If the eyeball is too long, the focused image falls short of the retina resulting in nearsightedness (myopia). If the eyeball is too short, the focused image falls behind the retina resulting in farsightedness (hyperopia).

Normal	**Farsighted**	**Nearsighted**
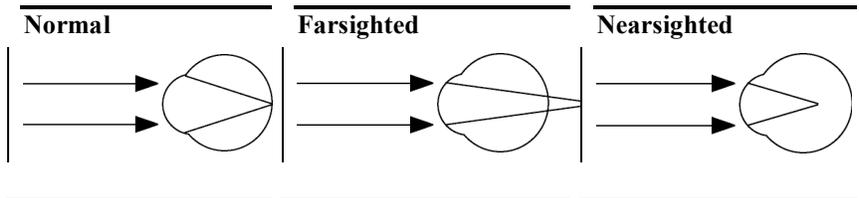
The refractive state is determined by the curvature of the front of the eye, the shape of the lens, and the length of the eye. Optical correction with glasses or contact lenses, with intraocular lenses when appropriate, can usually compensate for abnormalities in any or all of these factors.

early intervention

Early Intervention Policy ❖ Vision aids for children with diagnosed visual impairments can include such items as eyeglasses, external contact lenses, and magnifiers. Under federal and state law and regulations, assistive technology devices may be provided to children eligible for EIP when these devices are necessary to increase, maintain, or improve the functional capabilities of an infant or toddler in one or more of the following areas of development: cognitive, sensorimotor, communication, social/emotional, and adaptive/self-help.

Optical Correction for Refractive Errors

When considering optical correction for refractive errors in young children, it is important to be aware that not all conditions benefit from optical correction. Additionally, it may be difficult to fit young children with glasses, and compliance with wearing glasses may be a problem. It is also important to remember that corrective lenses can improve visual problems due to refractive errors (nearsightedness or farsightedness), but cannot improve decreased vision due to other problems.

It is important to recognize that laser refractive surgery, such as LASIK, is not approved in the United States for children under 18 years of age.

When selecting glasses for children under 3 years of age, it is important that:

▪ The lenses and frames meet national standards for safety set by the American National Standards Institute

▪ The frames are an age-appropriate size

▪ The frames are appropriately fitted and adjusted regularly

▪ Tints be used appropriately, particularly for children with achromotopsia and other conditions associated with glare sensitivity

For children with only one functional eye, it is recommended that protective lenses be worn at all times to protect the eye even if no optical correction is indicated.

It is recommended that bifocals be prescribed when accommodation is limited, such as for children with aphakia, i.e., without a lens following cataract surgery.

If a young child is not receptive to bifocals, it may be more useful to prescribe lenses to correct for near vision (as opposed to distant vision) because most of a child's visual world is up close.

INTERVENTIONS FOCUSED ON IMPROVING VISUAL FUNCTIONING

Visual function refers to how a child uses vision to perceive, respond, interact, and to function within the environment. Young children usually learn to use vision in the following sequences:

▪ From awareness to attention to understanding

▪ From lights to people to objects

▪ From moving objects to stationary objects

▪ From fixation to tracking

- From near to far
- From periphery to central
- From familiar to unfamiliar
- From parts to whole
- From simple to complex
- From large to small

General Approach for Improving Visual Function

General considerations for improving visual function

It is important to recognize that most children with vision impairment have visual responses that will be enhanced with practice. Much can be done to optimize whatever responses the child's visual eye condition will allow, and even a response to light or light and shadow can be helpful. The eye condition itself cannot be changed by vision stimulation, but the way the child uses his/her vision can be enhanced and optimized.

It is important to encourage the child to use vision in increasingly more advanced ways, as well as to find the limits to his/her visual abilities. It is also important that any program designed to improve visual functioning be structured to be consistent with the natural routines of the child's day and useful in the child's natural environments.

Environmental modifications to enhance visual function

Important environmental considerations include:

- Illumination
  - Use good lighting, but recognize that some conditions (e.g., achromatopsia and albinism) require reduced illumination

- Glare
  - Ensure the light source comes from behind the child
  - Use matte finishes (avoid glossy picture books)
  - Minimize glass/chrome and other highly reflective surfaces

- Color and contrast
  - Parents should wear clothes and makeup/nail color with high-contrast materials and complementary colors
  - Use #4 pencils and broad-tip markers

- Size
  - Determine the object size the child is able to see most easily (larger is not always better, especially for children with a limited visual field)
- Position of the object to be viewed
  - Place in the best area of the child's visual field
  - Place at the optimal distance for child's vision
- Position of the child
  - Securely positioned
  - Feet on the floor if sitting in a chair
  - Encourage some time in prone position (see ⊘ Note on page 108)

When structuring activities to facilitate and optimize functional skills and use of vision in children with vision impairment, it is important to:

- Use simple cues, repetition, and routines

- Present visual images or objects in isolation

- Pair visual information with another sensory cue (e.g., textures, smells, vibration, and sound) whenever possible

- Avoid overstimulation with visual clutter or too many sensory cues

- Use appropriate supportive seating

- Be aware of the child's visual preferences (e.g., color, field of vision, and shape and size of objects)

- Recognize that some children will be better able to complete a functional task if not required to maintain visual fixation throughout the task

For the child with useable vision, it is important to include activities to promote eye-hand coordination because this is the basis for manipulative play as well as for functional skills such as feeding and dressing.

Vision Stimulation

Vision stimulation includes techniques to stimulate the child's use of vision by teaching strategies to maximize the child's functional visual responses.

Vision stimulation techniques do not change visual acuity. They provide opportunities for the child to practice basic visual skills such as attention, localization, fixation, tracking, gaze shift, scanning, reaching, and grasping. The

purpose of vision stimulation is to strengthen the child's use of existing visual skills, improve efficiency of those skills, and expand the child's range of responses.

It is important to recognize that there is some controversy as to the effectiveness of vision stimulation for improving functional vision skills in young children with vision impairment, and only limited evidence was found to support the use of vision stimulation approaches.

Vision stimulation techniques

Vision stimulation techniques generally include the following activities designed for the purpose of helping the child:

- Acknowledge and respond to the presence of a visual stimulus (e.g., a moving object)

- Maintain prolonged attention to a visual target

- Fixate on a visual target that is moving closer to and further away from the child

- Perform visually directed motor responses, usually involving the hand or eye-feet coordination such as kicking a ball

- Align and increase range of motion of the eyes

- Follow a moving target

- Move the eye from one stationary target to another

- Use both eyes at the same time

It is important to consider the aspects of vision stimulation that parents can learn to provide and reinforce in the child's natural environments.

Vision therapy/vision training

There is some overlap of the use of the terms *vision stimulation*, *vision therapy*, and *vision training*. Even within professional disciplines, the terms are not always consistently defined and may be used interchangeably. Vision therapy/vision training typically refers to techniques that are used with older children and adults. Therefore, evaluation of approaches usually referred to as vision therapy/vision training is outside the scope of this guideline.

ORIENTATION AND MOBILITY TRAINING

The goal of orientation and mobility (O&M) instruction is for children with vision impairment to be able to travel in any environment as independently as possible.

Orientation is the process of utilizing sensory information to establish and maintain one's position in the environment.

Mobility is the process of moving safely, efficiently, and gracefully within one's environment.

Formal *orientation* skills include:

- Use of landmarks (orientation objects in the environment that are fixed and have a known location) and cues (orientation objects in the environment that are not fixed and may vary)

- Safe exploration of new areas

- Trailing (used to explore a new area by extending one's arm at a 45 degree angle in front of and to the side of one's body to follow a surface with one's hand and can also be performed with a long cane; can be used for mobility in a familiar area)

Formal *mobility* skills include:

- Guide techniques (process of moving from one location to another, with someone helping, by having the child hold onto the finger or wrist of an adult or the arm of another child)

- Protective techniques (upper forearm protection for the face and eyes, lower forearm protection for the mid-body and the locating of objects)

- Use of mobility devices, including precane devices (e.g., push toys or adapted long canes)

General O&M training considerations

Since mobility is difficult to teach in isolation, it is important for the O&M specialist to consult with other team members to determine which O&M skills would benefit the child.

It is important to teach O&M using direct body-to-body contact and mimicry (or mimicry with assistance). It is important to recognize that in general, multiple impairments and cognitive ability are not justification for preventing a child

from being considered for adaptive travel instruction. In the United States, professionally trained dog guides are not available to individuals younger than 16 years of age.

Developing the O&M plan

The frequency of service depends on the amount of residual vision and the child's age and history of milestone acquisition, as well as the need to access safe and independent travel. It is important to consider the expected future mode of travel:

▪ For children who will be able to use vision as a primary method of orientation and travel with the assurance of safety, a monthly consult and parental education may be sufficient

▪ For children who will travel primarily by sighted guide, cane, or adaptive tactile method, a more intensive program of consultation, parent education, and direct instruction may be needed

For most children younger than 3 years, it is recommended that O&M skills training be included as a part of the child's total intervention program.

Table 22:   Orientation and Mobility Training

Orientation and mobility training can focus on any of the following areas depending on the needs of the child and family:

Sensory Skills
- Vision (increased use of vision in a functional manner)
- Hearing
  - Localization (knowing where sounds come from)
  - Tolerance for auditory input (increasing the child's ability to respond appropriately to sound)
  - Echolocation (auditory feedback of reflected sounds from stationary objects)
- Touch
  - Tolerance for tactile investigation (increasing the child's ability to use touch in a functional manner)
  - Manipulation of objects
- Olfactory (sense of smell)

Body Image and Spatial Relations
- Body parts
- Body planes (top, bottom, front, back, sides)
- Spatial relations (concept formation of position, location, direction and distance from one's own body, relationship of objects to their environment)

Concept Development
- Size, color, shape, tactile qualities, and function of objects
- Time, distance, amount, and weight
- Environmental concepts
  - Indoor concepts (e.g., doors, windows, carpet, rugs, walls, stairs)
  - Outdoor concepts (e.g., sidewalks, driveways, corners, grass, trees)
  - Types of transportation (e.g., cars, buses, boats, airplanes)

Motor Development
- Gross motor skills (e.g., balance, strength, and movement)
- Fine motor skills (e.g., grasping, reaching, turning, pushing, and pulling)
- Purposeful and self-initiated movement
  - Purposeful movements (child-directed movements meant to obtain wants and needs in the environment)
  - Self-initiated movements (self-propelled ambulation of any type to help the child improve confidence and cognitive understanding of the world)
- Awareness and understanding of right/left side laterality

Parent education as a component of O&M training

It is recommended that parent education include an explanation of the functional implications of the child's eye condition and direct instruction in adaptive techniques, especially safe guiding methods. Guiding could involve verbal prompts or direct physical contact between the child and the adult.

It is important that parent education regarding mobility devices (both precane and long cane) emphasize consistent and safe use as recommended.

Important components of O&M parent education include:

- Working with the parents to find ways to encourage and ensure safe travel in the child's natural environment

- Ensuring the usual kind of childproofing as well as use of high contrast, texture, or lighting to delineate areas of concern

- Making the natural environment attractive to the child by placement of toys or moving the furniture, if needed, to encourage the child's movement and exploration.

Orientation and mobility devices and techniques

People with vision impairment use orientation and mobility devices (e.g., canes) and techniques (e.g., a human guide) to facilitate safe travel. Orientation and mobility devices can range from inexpensive or homemade low-tech devices to very expensive high-tech assistive devices. There are a variety of effective O&M devices that parents can easily make or purchase commercially, usually through specialty catalogs. Some O&M devices must be custom designed for the specific needs of the child. There are a limited number of safe techniques for children younger than 3 years old.

Considerations for cane use

It is important to recognize that precane devices include commercially available toys and homemade devices, and that many O&M specialists recommend commercially available push toys as precane devices.

It is recommended that a cane, if needed, be introduced when the child moves from cruising to independent walking. It is important to recognize that only an O&M specialist can recommend, select, and fit a cane. Cane selection is based on the child's height, speed of travel, length of stride, and stability of gait. The type of cane tip is chosen to facilitate specific cane or travel techniques.

It is important that the professional be sensitive to parental concerns regarding the potentially negative stereotype of a long white cane or precane mobility device.

Early Intervention Policy ❖ Items such as canes and wheelchairs can be assistive technology devices if they are being provided to children eligible for the EIP to increase, maintain, or improve the functional capabilities of an infant or toddler in one or more of the following areas of development: cognitive, sensorimotor, communication, social/emotional, and adaptive/self-help.

DEVELOPMENTAL INTERVENTIONS

During the first three years of life, children develop the foundation for future achievement in all developmental domains (cognitive, sensorimotor, communication, social/emotional adaptive/self-help). In the first months of life, the child learns primarily through observation and imitation. Developmental learning also occurs through exploration of one's surroundings and the new experiences that result from that exploration.

Young children with vision impairment will have difficulty learning from observation and imitation and will not be visually motivated to explore the environment. Therefore, to grow developmentally, young children with vision impairment need to learn how to interact with their environment using whatever residual vision they have as well as their other proprioception and kinesthetic senses (hearing, touch, smell, and taste).

Since children with vision impairment will be using alternate sensory systems to compensate for vision, it is important to modify the environment to encourage awareness of other sensory inputs and to facilitate learning. This can be accomplished through the use of touch, hearing, and movement (textured mats and toys, toys with auditory components, etc.).

General considerations for developmental interventions

Opportunities for exploration within a safe environment (e.g., an appropriate play space with clear boundaries) can help to facilitate learning through other senses, particularly touch, hearing, and movement. To promote learning through other senses, it is important to modify the environment to encourage awareness of other sensory inputs. To facilitate safe exploration of the environment, it is important to provide experiences that will help the child develop a sense of self in relation to the environment.

Important considerations for providing safe exploration include avoiding clutter, minimizing distracting noises, being aware of lighting, and remembering to talk to the child to help him or her conceptualize the environment and to increase awareness of other senses such as touch, taste, and smell.

It is important to provide repeated exposure to common objects and activities to facilitate learning. When learning occurs primarily through other senses, with decreased or absent accompanying visual input, it is usually more difficult to understand new objects and experiences. Therefore, repeated exposure is important.

For a child's sense of safety and control of self, it is important to be able to anticipate events. For children with vision impairment (and who have hearing), it is important to provide auditory cues before touching them.

For children with severe vision impairments and/or other disabilities in addition to vision impairment, it is important to use strategies that include coactive movement (performing tasks with the child seated in the teacher's lap). Initially, maximum body-to-body contact can be used as a way to demonstrate and provide practice in the completion of skills. Contact is gradually reduced to hand-under-hand or hand-over-hand prompting and then further reduced to verbal or simple touch cues.

Cognitive Development Intervention

Cognition includes the brain processes that allow us to remember, learn, think, act, feel emotions, and experience the environment. Cognitive processes are complex, diverse, and highly interrelated. Interventions targeting cognitive development focus on both global and specific cognitive skills such as attention to the environment, information processing, and memory.

Vision impairment may affect a child's cognitive development in the following ways:

- Reduced variety of experiences
- Reduced ability to negotiate/explore the environment
- Reduced control of the environment
- Reduced control of self in relation to the environment
- Dependence on secondhand information for things that are far away, larger than the child, or dangerous
- Difficulty gathering and organizing information about common objects and events resulting in delayed and/or poor concept development

Play activities are an important component of a young child's learning process and cognitive development. In particular, symbolic (pretend) play provides the foundation for abstract thinking and language. Young children with vision impairment often have delayed symbolic play skills because their ability to learn incidentally is impaired. In addition, it is difficult for them to make certain associations and develop concepts using tactual and auditory information.

Exposure to real events and objects provides the best foundation for symbolic play. However, there are also many play items that are commercially available for active use by young children with vision impairment that can help to promote the child's development.

General considerations for cognitive interventions

It is important to include the following in cognitive interventions:

- Activities to promote information processing skills such as cause-and-effect activities
- Both short- and long-term memory activities such as repetitive games, songs, and rhymes
- Motivating tasks and reinforcement strategies specific to the child

Cognitive intervention approaches

It is recommended that facilitation of cognitive skills begin as soon as possible. It is important to educate parents about the basic principles of child development and learning (Tables 23, 24, 25, and 26; pages 103-104) and about approaches that may help to stimulate cognitive development. For example, useful approaches for cognitive development might include:

- Using well-designed toys with highly reactive features (Table 25, page 103)
- Introducing children age 12 to 24 months to group learning experiences so they learn to model or imitate other children and adults
- Providing opportunities for exposure to new experiences and allowing the child to develop a natural interest in different activities (i.e., provide opportunities but do not force the interest)
- Using hand-under-hand or hand-over-hand guidance when introducing new activities to the child, and accompanying this manual guidance with descriptive language that relates to the child's own experiences

Table 23:   Basic Principles of Child Development and Learning / Learning Theories

Basic Principles of Child Development and Learning
- Children learn best when their physical needs are met and they feel psychologically safe and secure
- Children construct knowledge through active experimentation
- Children learn through social interaction with adults and other children
- Children learn through play
- Children's interests and "need to know" motivate learning
- Human development and learning are characterized by individual variation

Table 24:   Considerations for Promoting Exploration of the Environment

- Establishing easy-to-recognize boundaries
- Using securely fixed objects to delineate space and facilitate a sense of direction
- Differentiating between environments
- Creating multisensory environments
- Providing adequate and appropriate lighting
- Creating a good acoustical environment
- Maintaining enough consistency in the environment so that it is familiar and safe to explore
- Creating a defined play space (a playpen, tray, or placemat) with tactile boundaries and some fixed objects for safe exploration
- Positioning furniture to promote mobility (crawling, walking, etc.)

Table 25:   Important Characteristics of Play Items

- Textured features
- High contrast colors; separated primary colors
- Shiny, mirrored, reflective surfaces
- Features that light up
- Sounds that help child recognize the toy
- Sounds related to separate toy functions
- Immediate sound response

Table 25:   Important Characteristics of Play Items

- Imitative sound response
- Touch or sound activation
- Vibrating toys
- Three-dimensional toys with defined boundaries
- Differently shaped dials
- Structured play environment (e.g., puzzles with raised frames)

(Continued from previous page)

Table 26:   Age-Specific Approaches: Cognitive Interventions

Examples of intervention approaches that may help to stimulate cognitive development of children with vision impairment:

Age birth to 6 months

- Say the child's name often
- Verbally name and describe things in view
- Read and sing to the child regularly
- Use an infant carrier to keep the child near you during everyday activities
- Let the child touch objects that you are using, especially if they make sound (telephone, water, hairbrush, etc.)
- Use hand-over-hand and hand-under-hand prompting to encourage the child to explore objects with hands, bring hands together, move hands away from body and to mouth
- Allow the child to play on crinkly surfaces so that a sound is produced when the child moves (e.g., lay a towel over a paper bag)
- Use a play gym with items that are suspended low enough so that the baby's random movements will produce sounds
- Use wrist rattles on the hands and feet to add sound to random movements and to encourage exploration of the environment and body

Age 6 to 12 months

- Partially hide a toy under a towel or cloth within the infant's reach
- Hide a small, attractive toy in a box that's easy to open
- Show lots of pictures with colors or contrast
- Hang a mobile that moves when the child moves in the crib

Table 26:   Age-Specific Approaches: Cognitive Interventions

Age 12 to 24 months

▪ Allow the child to "help" with chores: throwing things away, washing dishes, folding laundry, and preparing meals

▪ Introduce the child to pretend play toys (toy kitchens, toy cars, and baby dolls) and associate them with the real thing when possible

  • Use gentle hand-over-hand prompting to demonstrate play with toys

  • Include play with cause-and-effect toys, container toys, and tactile books

▪ Introduce the child to group learning experiences because this is when children begin to be able to imitate other children and adults

▪ Include opportunities for interaction with other children in structured and semistructured activities to facilitate the attainment and reinforcement of cognitive skills

Age 24 to 36 months

▪ Increase opportunities to help with chores (putting groceries away, sorting pots and pans)

▪ Increase exposure to pretend play items (doll houses, toy kitchens, work benches, toy trucks, etc.) and symbolic play

(Continued from previous page)

It is important to be cautious about toy safety as children develop more independent motor skills such as rolling, reaching, mouthing and manipulating objects, and mobility skills. In particular, it is important to be aware of:

▪ Small objects (including removable items on toys or other objects that could be swallowed or cause the child to choke)

▪ Strings on toys (or other objects such as window blinds that could wrap around body parts)

▪ Sharp objects that could cut or puncture

Sensory and Motor Development Intervention

Vision impairment can affect early sensorimotor integration and development. Lack of vision can interfere with a child's exploration and understanding of the environment. Children with vision impairment tend to be less motivated to reach for and move toward objects because they cannot clearly observe the surrounding environment. This lack of motivation can lead to reduced activity and can affect both gross and fine motor development. Vision impairment also reduces the child's ability to observe and imitate the movements of others.

The degree to which the visual impairment affects a child's motor development depends on factors such as the severity of vision impairment, the child's overall health, other handicapping conditions, and the child's temperament. The most common problems young children have with gross motor development include:

- Poor muscle tone and poor posture
- Delayed transitional movements (getting to sitting from lying down, getting to standing from sitting, etc.)
- Delayed crawling and walking
- Immature gait patterns

Common problems with fine motor development include:

- Delayed reaching due to lack of visual information about where objects are in relation to self
- Delayed grasp and release of objects due to low muscle tone and inability to imitate
- Delayed wrist rotation due to low muscle tone and poor posture

General considerations for sensorimotor interventions

It is important that interventions focused on sensorimotor skills include:

- Coordinating eye-hand and eye-foot movements
- Teaching gestures and body language
- Moving toward desired objects

As the child progresses through the motor milestones, it is important that the environment be safe and familiar. It is important also to provide the child with opportunities that will develop confidence, encourage the use of sensorimotor skills, and promote generalization of skills to new environments (Table 27, page 108).

Gross motor development

It is important for infants with vision impairment to be positioned correctly and spend time in different positions (back, stomach, side-lying, and sitting) to promote good neuromuscular and musculoskeletal development. It is also important to keep the environment consistent as the child is learning new motor skills (e.g., do not rearrange the furniture).

Fine motor development

It is important to facilitate fine motor development during the child's natural daily routines such as feeding, bathing, dressing, and playing. Examples of activities that can help promote development of fine motor skills in young children with vision impairment include:

- Touching, reaching for, grasping, and releasing objects
- Banging hands and objects on a variety of surfaces
- Bilateral (both hands) manipulating of objects (twisting, turning, exploring)
- Developing spatial concepts through manipulation of objects (e.g., putting objects in/taking objects out of containers)

Sensory development

It is important to remember that a young child with vision impairment has to obtain information about the environment with an increased dependence on other senses. Some children with vision impairment may have an adverse response to certain textures or temperatures, a reluctance to touch anything placed in the hands, and/or gravitational insecurity. Some children may have hypersensitive sensory systems; others may have underdeveloped sensory systems.

Promoting the child's sensory awareness may include different sounds associated with different experiences or objects, different smells, objects with a variety of textures, and exploration of safe objects by mouthing. It is also important to help the child to develop body awareness through whole body activities such as swaddling, swinging, rolling, bouncing, and rocking.

Providing a child with sufficient sensorimotor activities may reduce or prevent development of stereotypical behaviors (e.g., repetitive mouthing, repetitive hand motions, eye poking, and/or nonfunctional use of toys).

Table 27: Age-Specific Approaches: Sensory and Motor Interventions

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Examples of intervention approaches that may help to stimulate sensory and motor development:

Age birth to 6 months

▪ Allow the child to spend some time in prone position (on stomach) to promote development of the head-lifting muscles needed for good postural control.

> ⊘ *Note: It is recommended that children not be in a prone position when sleeping. They should be closely monitored when prone because of the risk of sudden infant death syndrome associated with the prone position (American Academy of Pediatrics, 2005).*

▪ Change the baby's position frequently during the day so the baby will experience a variety of positions and locations, such as in a baby seat on the floor and on a table, playing on a blanket, or being carried in an infant carrier while a parent does household tasks.

Age 6-9 months

▪ Include gross motor activities to stimulate the baby's interest in moving and reaching, and to promote development of balance and protective extension
  • Introduce toys with textures and sounds that are interesting and enjoyable to the child and place them where they can be reached easily and safely
  • Roll the baby over a bolster or therapy ball
▪ To prevent delays in transitional movements such as getting to sitting independently, provide lots of simple movement activities
  • Bounce baby on the knee
  • Gently pull a blanket across the floor with the baby in a prone position

Age 9-12 months

▪ At this stage, children are capable of pairing a sound with an object and are also ready to begin crawling
  • Make sounds with favorite toys at progressively increasing distances to encourage the child to crawl
  • Use coactive movement (holding and moving together with the child)

Age 12-24 months

▪ Play games that promote body part identification
▪ Play gentle games such as gentle rolling or tickling (if enjoyed by the child)

Age 24-36 months

▪ Teach the child age appropriate play and art skills
  • Slides, swings, jungle gyms, tricycles, and balance beams
  • Finger painting with a variety of textures and smells
  • Throw, catch, and kick balls with bells inside
  • Hide-and-seek games
  • Paste objects of different shapes and textures

Communication Development Intervention

Much of communication is nonverbal and involves vision. Children with vision impairment have reduced access to the communicative means of eye contact, gaze, facial expression, and gesture. Infants with vision impairment appear more passive than sighted peers do and exhibit fewer behaviors that stimulate early interaction.

Communication with infants with vision impairment often requires interpretation of atypical signals and responses. For example, the quieting behavior or 'listening stance' of an infant who is totally blind may be misinterpreted as lack of interest or attention when it may indicate intense interest.

Vision impairment may affect both receptive and expressive language development as well as other communication skills. Development of communication skills may be affected because many aspects of communication (imitation, reciprocity, and object concept) are initially learned from visual cues. In addition, reduced eye contact may have an effect on attachment and socialization.

The impact of vision impairment on communication development may include:

- Reduced ability to initiate interactions or respond to interactions with others

- Difficulty associating verbal labels with tactual and auditory experiences

- Prolonged echolalia (repetition of sounds)

- Delayed use of pronouns, comparative adjectives, and prepositions (spatial relationship words)

- Difficulty with turn-taking and conversational rules

- A tendency toward using long strings of grammatically correct phrases that have little to do with what is going on or what others are talking about

It is important to understand that many children with vision impairment may also have delays in speech and language development. It is important to talk to young children with vision impairment to help facilitate the development of early communication. When speaking to children with vision impairment, it is important to:

- Use age-appropriate language

- Speak clearly and repeat or reword when necessary

- Use natural language, including words with visual reference such as "looks," "see," and "watch where you are going"

- Be specific about words that describe location (e.g., say put the toy "on the table" instead of put the toy "over there")

- Talk to children about what is going on in the environment, including descriptive words about color and placement

- Remember to allow for periods of silence to allow the child to process information, reflect, and initiate communication

- Make conversations meaningful and interesting using contextual cues and familiar vocabulary

- Help the child develop turn-taking skills

- Provide natural consequences for the child's requests and responses (e.g., "Would you like a cookie?" and if the child says "Yes," the child gets a cookie)

- Include the child in everyday activities and conversation about those activities

- Describe what the child is doing/touching and what you are doing/touching

- Match words and language to child's developmental age and ability

It is important to assist children with understanding how the tone and expression of language conveys emotional messages because the child does not have the ability to see facial expression. It is important for these children to experience facial expressions tactilely.

In addition to tactile experiences, language can be a substitute for vision in conceptualizing the environment. Therefore, it is important to verbally describe actions as well as objects. Tactile experiences should also be described for the purpose of enriching language and linking words to objects.

Table 28:   Age-Specific Approaches: Communication Interventions

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Examples of intervention approaches that may help to stimulate communication development:

Age birth to 3 months

- Speak to the child

- Respond to the child's cries and talk about what is happening ("You are hungry, time to eat")

- Listen for differences in cries and respond accordingly (the child may have a "hungry" cry that can be distinguished from a "wet" cry)

- Imitate reflexive vocalizations or respond to the child with speech

- Encourage the child to use mouth to explore safe objects

Age 3 to 6 months

- Imitate consonant and vowel sounds

- Encourage the child to explore your face tactilely when you are speaking

- Play tickling/bouncing games to elicit smiles and giggles

- Begin to prompt and reinforce when the child turns toward sound and speech

Age 6 to 12 months

- Encourage the child to imitate simple sounds

Age 10 to 12 months

- Encourage the child to say "Mama" and "Dada" meaningfully

- Prompt and reinforce following simple directions such as "Give it to me"

- Encourage the child to express needs with vocalizations and gestures rather than cries

Age 12 to 18 months

- Verbally name objects the child explores and plays with

- Increase the number and complexity of directions

- Prompt and reinforce use of words or word approximations

- Converse with the child and encourage jargon or baby talk

- Teach the names of body parts

- Teach use of concepts such as "More," "All gone," and "Help" at appropriate times

Age 18 to 24 months

- Encourage use of words to request objects and actions

- Prompt to follow directions using one or two spatial concepts (in, on, under, next to, inside)

- Encourage use of own name

- Ask "Yes/No" questions

- Encourage use of two-word phrases

Table 28:   Age-Specific Approaches: Communication Interventions

Age 24 to 36 months
- Encourage child to follow two-step directions
- Ask "Where" and "What are you doing" questions
- Encourage correct use of pronouns
- Encourage the use of three-word phrases

(Continued from previous page)

For children with communication delays or disorders, it may be helpful to use specialized communication devices (see "Assistive Technology," page 117).

It is important to recognize that all children can benefit from preliteracy/emerging literacy activities. These may include providing or adapting books and materials in large print, tactile or interactive auditory form such as:

- Children's books with simple pictures (for children who have form perception)

- Commercially available *Touch Me* books

- *Sources of Braille Children's Books and Magazines* (from the National Literacy Program, American Foundation for the Blind)

Adaptive/Self-Help Skills Intervention

Adaptive/self-help skills are those that children use to take care of themselves. These skills include sleeping, feeding, dressing, toileting, grooming, and caring for belongings. Because of sensorimotor difficulties, young children with vision impairment/blindness may have difficulty sleeping, eating, and/or feeding themselves.

General approach to adaptive/self-help interventions

When teaching adaptive/self-help skills to a young child with vision impairment, it is important to:

- Allow time for the child to investigate the activity and become familiar with the equipment and motions needed to successfully complete it

- Encourage the child to experiment and find the adaptation or technique that works best for the child

- Recognize that the method preferred by the adult teaching the skill may not be the most effective method for the child

It is important to understand that a child first learns a specific skill, then incorporates the skill into a daily routine, and finally uses the skill appropriately and independently.

Feeding skills - infants

It is important to recognize that feeding an infant with vision impairment is very much like feeding a sighted baby. The baby needs to feel safe and build trust in the feeder.

It is important to guide the baby's hands to the breast or bottle to encourage awareness of the feeding environment. Some infants may need preparation for feeding by stimulating the suck reflex, but it is important for the infant to be in charge of the initiation, pace, and timing of the feeding.

It is important to recognize that it may take longer for infants to give consistent cues about their feeding desires, and it may take longer for the parent to understand these cues.

It is important to recognize that infants with vision impairment may be at risk for oral and tactile sensitivity. For some children, patience and consistency may help to reduce or eliminate the oral hypersensitivity.

Feeding skills - older children

It is important for children with vision impairment to participate in the mealtime process as a member of the family. It is important to prepare foods for the child that are developmentally appropriate and to consider the visual limitations of the child when preparing the meal. It is also important to remember that for a child with vision impairment, the hands become the child's eyes when exploring and learning about the environment, including food.

Addressing sleeping problems

If a child with vision impairment is having a problem sleeping, it is important to determine whether there are any treatable medical problems that might be contributing to the problem. For example, allergies, asthma, or conditions that cause pain can disrupt sleep. Loud snoring or pauses in breathing in a young child always require medical evaluation.

Table 29:   Techniques for Developing Mealtime and Eating Skills

- Establish routines
- Talk about the food and let the child know food is coming
- Let the child help as much as possible and let the child control the pace
- Wait for the child's mouth to open and let the child lean forward into the spoon
- Go slowly when introducing new textures
- Encourage the child to keep hands on the cup
- Ensure there is adequate postural support when sitting
- Put food in the child's hands to encourage finger feeding
- Give choices
- Let the child use utensils when developmentally ready (a fork may be easier to use than a spoon)
- Use adaptive utensils, plates, and nonskid mats

Table 30:   Techniques for Developing Sleep Patterns

- Establish daytime routines (regular times for meals, activities, and naps)
- Develop bedtime rituals, establish consistent waking times
- Make reasonable adjustments to the child's nap schedule and bedtime to accommodate the child's natural sleep-wake cycles
- Set limits (and be consistent) on attention-getting behaviors and availability of interesting toys at bedtime
- Provide an environment (a cool, dark, quiet room) that promotes sleep
- Teach and reinforce self-soothing techniques rather than letting the child cry until falling asleep
- Use the crib/bed only for sleeping, limit awake time in bed
- Make the bedroom a sleep-only zone, or limit the activities in the bedroom to activities such as diaper changing and dressing
- Discourage excessive evening fluids, avoid drinks that contain caffeine
- Avoid medications to help the child sleep

Social/Emotional Development Intervention

Social development refers to how children learn to interact with others such as parents, siblings, friends, teachers, and playmates. Emotional development refers to how children learn to feel about themselves and others, and how they develop feelings of competency. Social-emotional skills develop along with sensory-motor, cognitive, language, and adaptive skills. Visual impairment may affect children's social-emotional development in the following ways:

- Reduced ability to anticipate what is about to happen
- Reduced ability to initiate and respond to interactions with others
- Increased need for the parent to encourage independent play and adaptive/self-help activities
- Reduced ability to imitate peer play in group activities
- Increased tendency for self-stimulation behaviors, such as eye-poking

General considerations for social/emotional interventions

It is important for parents, professionals, and others working with the child to learn how to approach the child in a way that does not startle or frighten. Therefore, it is important to remember to tell the child what you are going to do before doing it (picking the child up or touching the child). When beginning an activity, it is important to introduce yourself by name to help the child recognize you.

Because early attachment is critical for future social development and self-esteem, it is important for parents to understand that an infant with a significant vision impairment will interact with them differently than a sighted baby will. For example, infants with significant vision impairment:

- Cannot elicit attention or respond to attention by making eye contact
- Develop a social smile later than children with normal vision
- May be more passive and may not seek attention by crying, and therefore it may be more difficult to interpret their needs

It is important to understand that an infant with vision impairment does indeed crave and enjoy the parent's attention, even if the infant does not seem as responsive (cooing, vocalizing, crying) or as spontaneous as infants with vision.

It is important to recognize that a young child with severe vision impairment may not demonstrate fear of strangers or preference for his parents in the same way as sighted child. Very young children tend to need close proximity when using their sense of touch, smell, and hearing to identify different people.

Because young children with vision impairment may not be able to imitate their peers, it is important to teach them to play games to prepare them for group experiences with peers. For example, the child can be taught to play catch using a ball with a bell.

While peer interaction is important for the child's development, it is important to recognize that participating in activities involving large groups of children may create a demanding situation for a child with vision impairment. In large groups, it may be more difficult for children with vision impairment to discriminate auditory information.

Table 31:   Age-Specific Approaches: Social/Emotional Interventions

Examples of intervention approaches that may help to stimulate social/emotional development:

Age birth-6 months
- Keep the baby close, and talk, touch, and hold the baby as much as possible; the child will learn to know the parent through the senses of touch and hearing
- Look at the baby and talk and sing, even if the child does not look back; gently guide the child's head to turn toward the parent when the parent is speaking
- Use cuddling and gentle tickling to elicit smiles
- Use hand-over-hand or hand-under-hand prompting to encourage the child to explore facial expressions tactually
- Learn to read the baby's cues
- Set aside social times throughout the day to hold, talk, and play
- Watch the child closely during playtime to note subtle responses and indications of pleasure such as movement, change in breathing patterns, little smiles
- Sing and talk during feeding and diapering

Age 6-12 months
- Provide a safe, comfortable space where the child can move around independently
- Provide body-on-body play and dancing to help the child accept hand-over-hand or hand-under-hand prompting for dressing, feeding, and play skills

Age 12-24 months
- Increase exposure to play experiences with sighted children
- Provide as much playtime as possible with other young children

Age 24-36 months
- Encourage independence (keep favorite toys, clothes, and snacks in accessible areas)

ASSISTIVE TECHNOLOGY

A variety of assistive technology (AT) devices can help children with vision impairment perform many daily life activities. The goal of AT should be for the child to be able to function at a higher level of efficiency. AT devices can be either low technology or high technology.

Assistive technology definitions

The term *assistive technology* is used to describe a variety of devices that help individuals with disabilities engage in everyday activities that promote development and independence. The *Individuals with Disabilities Education Act* defines an *assistive technology device* as

> "Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child who has a disability."

Assistive technology service is defined as

> "Any service that directly assists a child who has a disability in the selection, acquisition, or use of an assistive technology device."

AT support includes purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices; selecting, designing, fitting, adapting, customizing, applying, maintaining, repairing, or replacing assistive technology devices; coordinating and using other therapies, interventions, or services with assistive technology devices; training or technical assistance for the child and family; and training for professionals or other individuals who provide services to the child.

General approach for assistive technology

It is recommended that the need for AT be considered for all children with vision impairment and that this need be reassessed on an ongoing basis.

Early Intervention Policy ❖ The intensity, frequency, and duration of EI services are determined through the Individualized Family Service Plan (IFSP) process. All services and assistive technology devices in the IFSP must be agreed upon by the parent and Early Intervention Official. When disagreements occur, parents can seek due process through mediation or an impartial hearing.

It is important to understand that recommending an AT device does not necessarily mean that the child will never achieve a certain developmental skill.

The use of assistive technology does not prevent the child from developing skills; it often provides an opportunity to learn new skills.

It is essential that professionals recommending AT:

- Be knowledgeable about AT in general as well as the particular device being recommended
- Be knowledgeable about the child's disability
- Consult with the child's family, vision professional, and other service providers
- Understand (and ensure the parents understand) that AT devices may be temporary and that their immediate benefit is to assist with the child's interaction with the environment and the accomplishment of new skills
- Ensure that all family members and service providers understand how and when the technology is to be used
- Provide training and customization to support the use of the device

When an AT device has been selected, it is important that appropriate training be provided for persons who are involved with the child, and that this training be conducted by professionals with appropriate expertise in the use of the device.

It is important to monitor the use of the AT device to ensure that it meets the needs of the child and family, and that it is changed as the child's needs change.

Assistive technology devices (AT)

It is important to recognize that low-tech devices can be as effective as high-tech devices, without the complexity and required training. Low-tech devices such as push toys for walking may also be more typical of what other children use in their natural play environments.

It is important to recognize that many commercial products have not been scientifically tested for use by young children with vision impairment. It is also important to recognize that some AT devices are more appropriate for older children or children at a higher developmental level. Parents and professionals need to be informed to ensure that the AT device is appropriate and safe for the child. Table 32 (page 119) provides examples of assistive devices that are helpful for young children with vision impairment.

Examples of AT devices that may not be appropriate for young children include:

- Devices worn on the head, such as sonic guide devices
- Telescopic devices
- High-technology optical and electronic devices and high-technology computerized voice output systems

Table 32:   Examples of Assistive Devices for Young Children With Vision Impairment

AT Category	Examples
Vision Aids	▪ Eyeglasses ▪ External contact lenses ▪ Magnifiers
Positioning Devices	▪ Wedges, rolls ▪ Seat inserts ▪ Adapted seating systems ▪ Adapted potty chairs
Premobility and Mobility Devices	▪ Adapted push toys, canes ▪ Walkers ▪ Scooter boards
Play/Learning Aids	▪ Reactive play items with music, sound, vibratory feedback ▪ Switches, adapted switch toys ▪ Items with differentiated access areas ▪ Adapted computer peripherals (switch interface, adapted keyboards) ▪ Tactile books, puzzles
Access Materials	▪ Attachments that bring items closer to the child (plastic links) ▪ Extenders that help children locate and access toy features (page turner) ▪ Stabilizers or confinement materials that prevent a toy from moving out of the child's reach ▪ Highlighters placed on surfaces to make things easier to find (fluorescent tape, locator dots, various textures)
Communication Devices	▪ Communication boards with adapted labels (textures, contrast, line drawings) ▪ Single, sequential, and multiple recordable message devices

OTHER INTERVENTION APPROACHES

When making a decision about whether to use a particular intervention for a young child with vision impairment, it is important that parents consider information about the efficacy of the intervention as well as information about the potential physical and other risks of the intervention.

There is no current scientific evidence to support the use of the following interventions to improve vision in young children with vision impairment. It is recommended, therefore, that the following interventions not be used:

- Hyperbaric oxygen treatment

- Light therapy

- Transplants and implants

- Gene therapy

- Nutritional and dietary supplements

Hyperbaric oxygen

Hyperbaric oxygen therapy (HBOT) physically dissolves extra oxygen into the blood plasma. Use of HBOT has been reported for the treatment of many conditions, including decompression sickness in SCUBA divers. This therapy has been used by proponents for the care of preterm babies in order to reverse hypoxia and control periventricular hemorrhages.

Light therapy

Light therapy (also called phototherapy) is most commonly used as therapy for conditions such as hyperbilirubinemia (jaundice) in newborns and seasonal affective disorders (SAD). For treatment of vision-related problems, light therapy may be referred to as syntonics. Treatment often requires several 20- to 30-minute sessions per week.

Transplants and implants

Research is currently being conducted on animals and adult humans using cell and tissue transplants for stabilizing or reversing a variety of ocular diseases. Research is being conducted also on the development of computer chip implants as artificial eyes. This research is in its infancy, and these technologies are not available at this time.

Gene therapy

Gene therapy refers to the attempt to target treatment for a specific condition on the gene or genes responsible for the disorder. There are two kinds of gene therapy. One approach is to attempt to alter the genes in the eggs and sperm or in the fertilized egg. The other approach is directed to tissues or organs in the individual with the condition. This approach is currently undergoing clinical trials directed primarily toward inherited metabolic diseases.

The U.S. Food and Drug Administration has not yet approved any human gene therapy products for sale. Current gene therapy is experimental and has not proven very successful in clinical trials. There are several obstacles to effective gene transfer. Clinical trials underway are utilizing new techniques to overcome these barriers. The recent completion of a draft genetic sequence by the scientists involved in the Human Genome Project holds great promise for the identification of genes involved in genetic eye disease. These developments have not yet resulted in new available treatments for children with vision impairment.

Nutritional and dietary supplements

Nutritional and dietary supplements, including megavitamins and herbs, are often considered for treating a variety of conditions, especially when other treatments offer little benefit. While good nutrition is important for good health and vision, there is no evidence that nutritional or dietary supplements improve vision in young children with vision impairment, with the exception of children with specific metabolic disorders and vitamin deficiencies.

Early Intervention Policy ❖ Therapies such as hyperbaric oxygen therapy, gene therapy, growth hormone therapy, vitamin therapy, or nutritional/dietary supplements are not reimbursable costs under the Early Intervention Program. In addition, the EIP does not cover the costs of other medical interventions, surgical procedures, or primary health care services that are needed by any child.

APPENDIX A: DEVELOPMENTAL ASSESSMENT TESTS

Tests for identification and assessment of young children with vision impairment

Appendix A Contents

Battelle Developmental Inventory (BDI)

Type of Test	Criterion-based and norm-referenced with hearing norms, using verbal instructions, and nonvocal responses. This provides a measure of developmental skills across five domains. A screening test with 28% of the items included. Allows for multisource assessment.
Purpose	To identify children with disabilities, strengths and weaknesses of children without disabilities, appropriate instructional plans for individual children, and to monitor child's progress.
Age Range	Birth to 8 years old
Components	Test has one form with five domains: personal-social, adaptive, motor, communication, and cognitive. Some testing materials are supplied with manual.
Scoring	Items are scored from 0-2 based on interview of caregivers or teachers, observation, and/or task performance. Emerging skills are included. Scores include percentile ranks for the overall test, domains, and some sub-domains. Standard scores can be obtained for conversion of percentile scores.
Time	1-2 hours for entire test, 0-30 minutes for screening test, 30 minutes for cognitive domain.
Standardization	A total of 800 children were selected based on region, gender, race, and urban/rural residency according to 1981 census statistics.
Training	Not specified

Bayley Scales of Infant Development II (BSID-II) Second Edition 1993 (Third Edition Published 2005)

Type of Test	A standardized assessment of infant development.
Purpose	The test is intended to measure a child's level of development in three domains: cognitive, motor, and behavioral.
Age Range	Birth to 42 months old
Components	The BSID-II consists of three scales: mental, motor, and behavior rating scales.
	The test contains items designed to identify young children at risk for developmental delay.
Scoring	An "item set" based on age is presented in a specific order and scored with some examiner flexibility. Standardized scores are reported for either the Mental Development Index (MDI) or the Performance Development Index (PDI).
Time	From 30 to 60 minutes
Standardization	BSID normative data reflects the U.S. population in terms of race/ethnicity, infant's gender, education level of parents, and demographic location of the infant.
	The Bayley was standardized on 1,700 infants, toddlers, and preschoolers between 1 and 42 months of age.
	Norms were established using samples that did not include disabled, premature, and other at-risk children. Corrected scores may be used for these higher risk groups, but their use is controversial.
Training	Appropriate training and experience are necessary to correctly administer and score the assessment.

Carolina Curriculum for Infants and Toddlers With Special Needs (CCITSN)

Purpose	A curriculum-based assessment used to determine curricular interventions for infants and toddlers with mild to severe special needs.
Age Range	Birth to 24-month level of development
Components	Curriculum is divided into 26 teaching sequences that cover the 5 developmental domains. Specific activities and adaptations appropriate for diverse functional levels and disabilities, including perceptual impairment and motor delay, are included.
	Instructional activities are process oriented, providing suggestions for incorporating activities into daily care and modifications for infants with motor, visual, or hearing impairments.
Scoring	Items scored pass-fail. Based on examiner's judgment, infant's performance may also be scored as partially successful. Child must successfully perform an item for 3 of 5 trials to reach teaching criterion.
Time	Not specified
Standardization	Criterion-referenced. Scores not norm-referenced. Field-tested the curriculum and assessment with details provided. Interrater reliability of 96.9% agreement reported for first edition.
Training	Formal training not required. Designed to be administered by professionals from numerous disciplines.

Denver Developmental Screening Test: Denver II (DDST)

Type of Test	General development test.
Purpose	Primarily designed to identify children with delays in multiple domains who are at risk for mental retardation. Can also be administered to monitor the development of infants who attend a high-risk infant follow-up clinic.
Age Range	Birth to 6 years
Components	Denver II retains structure of DDST, in which items are divided into four domains: personal-social, fine motor adaptive, language, and gross motor. Items were expanded from 105 to 125, and 5 "test behavior" items were added.
Scoring	Directions for administration are clear. Test is easy to administer, requires no special equipment, and is acceptable to both children and parents. Items arranged by domain and age level on a single-page screening form. Items are scored "pass," "fail," "no opportunity," or "refusal." Results are interpreted as normal, abnormal, questionable, or untestable.
Time	Can be administered in less than 20 minutes
Standardization	Technical manual includes details of revision and standardization.
Training	Most likely users of test are physical therapists working in early intervention who are involved in child find programs or in the intake process. Separate technical manual includes chapter on training.

Hawaii Early Learning Profile (HELP)

Purpose	Designed as a family-centered assessment instrument intended to facilitate comprehensive assessment by an interdisciplinary team.
Age Range	Children who function at or below 36 months of age
Components	Test based on normal developmental sequence. Seven functional areas are assessed using a checklist of 685 developmental items. Functional areas include regulatory/sensory organization, cognitive, language, gross and fine motor, social-emotional, and self-help.
Scoring	Infant's performance on an item is scored as pass-fail or partially successful based on examiner's judgment. Scores are used, with qualitative description of the child's developmental skills and behaviors, to determine approximate developmental level within major developmental domains.
Time	Not specified
Standardization	Field-tested the curriculum and assessment, but details not provided. Not standardized but uses developmental sequences from standardized tests and developmental scales.
Training	Assessments designed to be administered by professionals from different disciplines. Formal training not required.

Mullen Scales of Early Learning

Type of Test	Standardized assessment tool that identifies specific areas of delay. Also used with accuracy for assessing young children with hearing loss.
Purpose	Assesses general cognitive functioning, visual organization skills, and expressive and receptive language to identify specific areas of delay.
Age Range	Birth to 68 months
Components	Consists of the following 5 scales: gross motor, visual reception, fine motor, receptive language, and expressive language.
Scoring	Each scale is scored yielding domain-specific information separately (mean=100, standard deviation=10). A cognitive score can be obtained by excluding the gross motor scale (mean=100, standard deviation=15). Scores may be reported as age equivalents or percentile ranks.
Time	Depends on the age of the child. The test takes approximately 15 minutes when administered to a 1-year-old and 30 minutes when administered to a 3-year-old.
Standardization	On a sample of 1,231 infants and toddlers. Sample was stratified by age, gender, race, parental occupation, and geography.
Training	Minimal training is required. Test administration can be performed by professionals with early childhood experience.

Oregon Project for the Blind and Visually Impaired

Type of Test	Designed specifically to assess the developmental level for children who are visually impaired or blind.
Purpose	Provides assessment tools to obtain child's developmental level and record the acquisition of new skills.
Age Range	Birth to 6 years
Components	The Skills Inventory assesses the child's development in the following 8 categories: cognitive, language, visual, early age compensatory, socialization, self-help, gross motor, and fine motor. The Student Profile provides an overall view of the child's performance per skill category in relation to other skill categories and the child's chronological age.
Scoring	Sections can be administered in any order. It is not recommended or necessary to complete all sections. The number of skills in each level is calculated. Percentages are determined by age level using a percentage conversion chart. Percentage per skill category and chronological age are graphed to generate a profile.
Time	Varies depending on the number of sections completed and age of child.
Standardization	Not used as a normative assessment instrument.
Training	A manual is available with detailed instructions about administration of the test.

Pediatric Evaluation of Disability Inventory (PEDI)

Purpose	A judgment-based functional assessment that samples content in domains of self-care, mobility, and social function. Functional assessment of infant and toddler through interview with parents.
Age Range	Designed for children between ages 6 months and 7.5 years, but can be used for older children if functional abilities fall below those expected of typically developing 7-year-old children.
Components	Measures both capability and performance on 197 functional skill items.
Scoring	The level of assistance to complete specific activities is measured.
Time	Direct administration takes 20 to 30 minutes. Administration by parent report or interview can take up to 45 minutes.
Standardization	Standardized on 412 children and families stratified by age, gender, race-ethnicity, parent education, community size, and other socio-economic factors.
Training	Training requirements included in the manual.

Vineland Adaptive Behavior Scales (VABS)

Type of Test	Assesses adaptive skills (personal and social sufficiency) from birth to adulthood.
Purpose	To assess communication, daily living skills, socialization, and motor skills domains.
Age Range	Birth to 18 years old
Components	Three forms are available: the Interview Edition Survey with 297 items, the Expanded Form with 577 items, and the Classroom Edition with 244 items.
Scoring	A respondent (a parent, a teacher, or another professional) who knows the individual well answers behavior-oriented questions about the individual's adaptive behavior.
Results	Can be expressed as a standard score, percentiles, or age equivalents in each domain, as well as in the form of an Adaptive Behavior Composite.
Time	Approximately 90 minutes
Standardization	The Interview Edition Survey and Expanded Form were standardized on 3,000 individuals from birth through 18 years old.
	Separate norms are available for children with mental retardation, emotional disorders, and physical handicaps.
	An additional 3,000 children ranging in age from 3 to 12 years old served as the normative group for the Classroom Edition.
Training	Administration requires appropriate training and professional experience.

APPENDIX B: EARLY INTERVENTION PROGRAM INFORMATION

New York State

B-1: EARLY INTERVENTION PROGRAM DESCRIPTION

The Early Intervention Program (EIP) is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead state agency responsible for the Early Intervention Program.

Early Intervention services can help families:

- Learn the best ways to care for their child
- Support and promote their child's development
- Include their child in family and community life

Early Intervention services can be provided anywhere in the community, including:

- A child's home
- A child care center or family day care home
- Recreational centers, play groups, playgrounds, libraries, or any place parents and children go for fun and support
- Early childhood programs and centers

Parents help decide:

- Appropriate early intervention services for their child and family
- Early intervention outcomes that are important for their child and family
- When and where their child and family will receive early intervention services
- Who will provide services to their child and family

Early Intervention Officials (EIO)

In New York State, all counties and the City of New York are required by New York State Public Health Law to appoint a public official as their Early Intervention Official.

The EIO is the person in the county responsible for:

- Finding eligible children
- Ensuring that eligible children have a multidisciplinary evaluation
- Appointing an initial service coordinator to help families with their child's multidisciplinary evaluation and Individualized Family Service Plan (IFSP)

- Ensuring that children and families receive the early intervention services in their IFSPs
- Safeguarding child and family rights under the Program

The EIO is the "single point of entry" for children into the EIP. This means that all children under three years of age who may need early intervention services must be referred to the EIO. In practice, EIOs have staff assigned to receive child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the EIO (see Step 1of Early Intervention Steps, page 140). Sometimes, someone else will be the first to raise a concern about a child's development. New York State Public Health Law requires certain professionals (primary referral sources) to refer infants and toddlers to the Early Intervention Official when a developmental problem is suspected. However, no professional can refer a child to the EIO if the child's parent refuses the referral.

Service Coordinators

There are two types of service coordinators in New York State: an initial service coordinator and an ongoing service coordinator. The initial service coordinator is appointed by the EIO. The initial service coordinator helps with all the steps necessary to get services, from the child's multidisciplinary evaluation to the first IFSP.

Parents are asked to choose an ongoing service coordinator as part of the first IFSP. The main job of the ongoing service coordinator is to ensure that the child and family receive the services in the IFSP. The ongoing service coordinator will also help change the IFSP when necessary and ensure that the IFSP is reviewed on a regular basis. Parents may choose to keep the initial service coordinator, or they can choose a new ongoing service coordinator.

Eligibility

Children are eligible for the EIP if they are under three years old AND have a disability OR developmental delay. A disability means that a child has a diagnosed physical or mental condition that often leads to problems in development, such as Down syndrome, autism, cerebral palsy, vision impairment, or hearing loss.

A developmental delay means that a child is behind in at least one area of development, including:

- Physical development (growth, gross and fine motor abilities)

- Cognitive development (learning and thinking)
- Communication (understanding and using words)
- Social-emotional development (relating to others)
- Adaptive development (self-help skills, such as feeding)

A child does not need to be a U.S. citizen to be eligible for services, and there is no income "test" for the EIP. The child and family must be residents of New York State to participate.

How is Eligibility Decided?

All children referred to the EIO have the right to a free multidisciplinary evaluation to determine if they are eligible for services. The multidisciplinary evaluation also helps parents to better understand their child's strengths and needs and how early intervention can help.

A child who is referred because of a diagnosed condition that often leads to developmental delay, such as Down syndrome, will always be eligible for early intervention services.

If a child has a diagnosed condition, he or she will still need a multidisciplinary evaluation to help plan for services. If a child has a delay in development and has no diagnosed condition, the multidisciplinary evaluation is needed to determine whether the child is eligible for the program. A child's development will be measured according to the "definition of developmental delay" set by New York State.

Services

Early intervention services are:

- Aimed at meeting children's developmental needs and helping parents take care of their children
- Included in an IFSP agreed to by the parent and the EIO

Early intervention services include:

- Assistive technology services and devices
- Audiology
- Family training, counseling, home visits, and parent support groups
- Medical services for diagnostic or evaluation purposes only
- Nursing services
- Nutrition services

- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination services
- Social work services
- Special instruction
- Speech-language pathology
- Vision services
- Health services needed for children to benefit from other early intervention services
- Transportation to and from early intervention services

Provision of Services

Only qualified professionals, i.e., individuals who are licensed, certified, or registered in their discipline and approved by New York State, can deliver early intervention services. All services can be provided using any of the following service models:

- Home- and community-based visits. In this model, services are provided to a child and/or parent or other family member or caregiver at home or in places such as a relative's home, child care center, family day care home, play group, library story hour, or other places parents go with their children.

- Facility- or center-based visits. In this model, services are provided to a child and/or parent or other family member or caregiver where the service provider works, such as an office, a hospital, a clinic, or early intervention center.

- Parent-child groups. In this model, parents and children get services together in a group led by a service provider. A parent-child group can take place anywhere in the community.

- Family support groups. In this model, parents, grandparents, siblings, or other relatives of the child get together in a group led by a service provider for help and support, and to share concerns and information.

- Group developmental intervention. In this model, children receive services in a group setting led by a service provider or providers without parents or caregivers present. A group means two or more children who are eligible for early intervention services. The group can include children without disabilities and take place anywhere in the community.

Family Concern

1. Referral *(unless parent objects)*
- Referral source or parent suspects child of having developmental delay or disability
- Family informed of benefits of Early Intervention Program
- Child referred to EIO within 2 days of identification
- Early Intervention Official assigns Initial Service Coordinator

REFERRAL

2. Initial Service Coordinator
- Provide information about EIP
- Inform family of rights
- Review list of evaluators
- Obtain insurance/Medicaid information
- Obtain other relevant information

COORDINATOR

3. Evaluation*
- Determine eligibility
- Family assessment, optional
- Gather information for IFSP
- Summary and report submitted prior to IFSP

4. The IFSP Meeting*(if child is eligible)*
- Family identifies desired outcomes
- Early Intervention services specified
- Develop written plan
- Family and EIO agree to IFSP
- Identify Ongoing Service Coordinator
- EIO obtains social security number(s)

IS CHILD ELIGIBLE?

EVALUATION

May access due process procedures

6. Transition

- Plan for transition included in IFSP
- Transition to:
  - services under Section 4410 of Education Law (3-5 system)

  OR
  - other early childhood services, as needed

TRANSITION

Areas of Development

- cognitive
- physical (including vision and hearing)
- communication
- social/emotional
- adaptive development

REVIEW AHEAD

5. IFSP – Review Six Months /Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies, and/or services
- If parent requests, may review sooner:
  - If parent requests an increase in services, EIO may ask for independent evaluation

Early Intervention Services*

- assistive technology devices and services
- audiology
- family training, counseling, home visits and parent support groups
- medical services only for diagnostic or evaluation purposes
- nursing services
- nutrition services

- occupational therapy
- physical therapy
- psychological services
- service coordination
- social work services
- special instruction
- speech-language pathology
- vision services
- health services
- transportation and related costs

THE IFSP MEETING

Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.

Revised 12/04

REIMBURSEMENT

All services are provided at no cost to families. The EIP accesses Medicaid and commercial third party insurance when parents' policies are regulated by the state. County and state funds cover the costs of services.

For more information about the New York State laws and regulations that apply to early intervention services, contact the Bureau of Early Intervention.

New York State Department of Health
Bureau of Early Intervention
Corning Tower Building, Room 287
Empire State Plaza
Albany, NY 12237-0660

518-473-7016

http://www.health.ny.gov/community/infants_children/early_intervention/

bei@health.state.ny.us

B-2: OFFICIAL EARLY INTERVENTION PROGRAM DEFINITIONS

These definitions are excerpted from New York State Code of Rules and Regulations, §69-4.1, §69-4.10 and §69-4.11. For a complete set of the regulations governing the Early Intervention Program, contact the New York State Department of Health, Bureau of Early Intervention, at (518) 473-7016 or visit the Bureau's Web page:
http://www.health.ny.gov/community/infants_children/early_intervention/

Sec. 69-4.10 Service Model Options

(a) The Department of Health, state early intervention service agencies, and early intervention officials shall make reasonable efforts to ensure the full range of early intervention service options are available to eligible children and their families.

    (1) The following models of early intervention service delivery shall be available:

        (i) home and community based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at the child's home or any other natural environment in which children under three years of age are typically found (including day care centers and family day care homes);

        (ii) facility-based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at an approved early intervention provider's site;

        (iii) parent-child groups: a group comprised of parents or caregivers, children, and a minimum of one appropriate qualified provider of early intervention services at an early intervention provider's site or a community-based site (e.g., day care center, family day care, or other community settings);

        (iv) group developmental intervention: the provision of early intervention services by appropriate qualified personnel to a group of eligible children at an approved early intervention provider's site or in a community-based setting where children under three years of age are typically found (this group may also include children without disabilities); and

        (v) family/caregiver support group: the provision of early intervention services to a group of parents, caregivers (foster parents, day care staff, etc.) and/or siblings of eligible children for the purposes of:

            (a) enhancing their capacity to care for and/or enhance the development of the eligible child; and

            (b) providing support, education, and guidance to such individuals relative to the child's unique developmental needs.

Sec. 69-4.1 Definitions

(b) *Assessment* means ongoing procedures used to identify:

    (1) the child's unique needs and strengths and the services appropriate to meet those needs; and

    (2) the resources, priorities, and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability.

(g) *Developmental delay* means that a child has not attained developmental milestones expected for the child's chronological age adjusted for prematurity in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social/emotional, or adaptive development.

    (1) A developmental delay for purposes of the Early Intervention Program is a developmental delay that has been measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures, and/or instruments and documented as:

        (i) a twelve month delay in one functional area; or

        (ii) a 33% delay in one functional area or a 25% delay in each of two areas; or

        (iii) if appropriate standardized instruments are individually administered in the evaluation process, a score of at least 2.0 standard deviations below the mean in one functional area or score of at least 1.5 standard deviation below the mean in each of two functional areas.

(ag) *Parent* means a parent by birth or adoption, or person in parental relation to the child. With respect to a child who is a ward of the state, or a child who is not a ward of the state but whose parents by birth or adoption are unknown or unavailable and the child has no person in parental relation, the term "parent" means a person who has been appointed as a surrogate parent for the child in accordance with Section 69-4.16 of this subpart. This term does not include the state if the child is a ward of the state.

(aj) *Qualified personnel* are those individuals who are approved as required by this subpart to deliver services to the extent authorized by their licensure, certification, or registration, to eligible children and have appropriate licensure, certification, or registration in the area in which they are providing services including:

    (1) audiologists;

    (2) certified occupational therapy assistants;

    (3) licensed practical nurses, registered nurses, and nurse practitioners;

(4)   certified low vision specialists;

(5)   occupational therapists;

(6)   orientation and mobility specialists;

(7)   physical therapists;

(8)   physical therapy assistants;

(9)   pediatricians and other physicians;

(10) physician assistants;

(11) psychologists;

(12) registered dieticians;

(13) school psychologists;

(14) social workers;

(15) special education teachers;

(16) speech and language pathologists and audiologists;

(17) teachers of the blind and partially sighted;

(18) teachers of the deaf and hearing handicapped;

(19) teachers of the speech and hearing handicapped;

(20) other categories of personnel as designated by the Commissioner.

(al)   *Screening* means a process involving those instruments, procedures, family information and observations, and clinical observations used by an approved evaluator to assess a child's developmental status to indicate what type of evaluation, if any, is warranted.

Sec. 69-4.11 (a)(10) Individualized Family Service Plan (IFSP)

(10) The IFSP shall be in writing and include the following:

(i)   a statement, based on objective criteria, of the child's present levels of functioning in each of the following domains: physical development, including vision and hearing; cognitive development; communication development; social or emotional development; and adaptive development;

(ii) a physician's or nurse practitioner's order pertaining to early intervention services which require such an order and which includes a diagnostic statement and purpose of treatment;

(iii) with parental consent, a statement of the family's strengths, priorities and concerns that relate to enhancing the development of the child;

(iv) a statement of

1. the major outcomes expected to be achieved fro the child and the family, including timelines, and

2. the criteria and procedures that will be used to determine whether progress toward achieving the outcomes is being made and whether modifications or revisions of the outcomes or services is necessary.

**B-3: TELEPHONE NUMBERS FOR MUNICIPAL EARLY
INTERVENTION PROGRAMS**

Please visit our Web pag at
http://www.health.ny.gov/community/infants_children/early_intervention/

APPENDIX C: ADDITIONAL RESOURCES

> **Note:** *Inclusion of these organizations is not intended to imply an endorsement by the guideline panel or the New York State Department of Health. The guideline panel has not specifically reviewed the information provided by these organizations.*

American Academy of Ophthalmology (AAO)
P.O. Box 7424   (415) 561-8500
San Francisco, CA 94120-7424   Fax (415) 561-8533
www.aao.org

American Association for Pediatric Ophthalmology
and Strabismus (AAPO&S)
P. O. Box 193832   (415) 561-8505
San Francisco, CA 94119-3832   Fax (415) 561-8531
www.aapos.org

American Foundation for the Blind (AFB)
11 Penn Plaza, Suite 300   (212) 502-7600
New York, NY 10001   Fax (212) 502-7777
www.afb.org

American Optometric Association (AOA)
243 North Lindbergh Boulevard   (800) 365-2219
St. Louis, MO 63141   (314) 991-4100
www.aoa.org   Fax (314) 991-4101

American Printing House for the Blind (APH)
PO Box 6085   (800) 223-1839
Louisville, KY 40206-0085   (502) 895-2405
www.aph.org   Fax (502) 899-2274

National Eye Institute (NEI)
2020 Vision Place   (301) 496-5248
Bethesda, MD 20892-3655   Fax (301) 402-1065
www.nei.nih.gov

National Organization for Albinism and
Hypopigmentation (NOAH)
PO Box 959   (800) 473-2310
East Hampstead, NH 03826-0959   (603) 887-2310
www.albinism.org   Fax (800) 648-2310

New York State Office of Children and Family Services
52 Washington Street   (518) 473-7793
Rensselaer, NY 12144-2796   (866) 871-3000
www.ocfs.state.ny.us   TDD (866) 871-6000
                                                                       Fax (518) 486-7550

New York State Commission for the Blind and Visually
Handicapped
52 Washington Street   (518) 474-6812
Rensselaer, NY 12144-2796   (866) 871-3000
www.ocfs.state.ny.us/main/cbvh   TDD (866) 871-6000

APPENDIX D: SUMMARY OF RESEARCH FINDINGS: PANEL CONCLUSIONS

Assessment: Vision Screening Devices

Photoscreeners

1. Some photoscreeners (the Medical Technology and Innovations, the Fortune VRB) are not useful as general screeners in some samples because:
    *   Too many children who have risk factors for amblyopia are not identified
    *   Interpretation and grading of the photographs can be subjective, leading to variation in results (Cooper 1999, Weinand 1998)
2. When evaluating the efficacy of photoscreener results, a lack of information about pass/fail criterion and good statistical analysis of data makes it difficult to interpret the results of the study (Ottar 1995).
3. Photoscreener results are most useful when sensitivity and specificity are reported individually by specific condition (e.g., media opacity, high refractive errors, strabismus) (Tong 2000).
4. Rater results and interpretations vary little when comparing scores by groups based on professions (e.g., pediatricians vs. ophthalmologists) using the Medical Technology and Innovations photoscreener or the Auckland model (Optocam) photorefractor (Hope 1994, Tong 1998).
5. There are marked differences in the sensitivity and specificity between well-trained individual raters within the same profession or a small number of raters not grouped by profession (Simons 1999, Tong 1998).

Photorefractors (a type of photoscreener)

6. The off-axis photorefractor provides better analysis than the on-axis refractor (Hamer 1992).
7. The on- and off-axis photorefractors are:
    *   Useful for finding refractive errors only
    *   Not useful for identifying some conditions since only one eye is measured at a time
    *   Not commercially available and therefore not applicable for widespread screening (Atkinson 1984, Hamer 1992, Hope 1994)
8. The Visiscreen 100 is an outdated photorefractor. The following principles, however, remain the same. Photorefractor results:
    *   Are better with eye drops (cycloplegia)
    *   Are not good for children younger than 3 months of age, but are improved with the use of eye drops (cycloplegia)

- Can also identify astigmatism and provide information about refractive errors. However astigmatism found in isolation is not a major cause of amblyopia and not as important to identify at an early age (Atkinson 1984, Hodi 1994, Preslan 1993)

9. The PR2000 photorefractor:
   - Is designed for refraction, not screening
   - Is difficult to use in children younger than 36 months of age since they must attend to an object (fixate) for longer periods of time
   - May provide accurate measurements when the child is able to fixate during photorefraction (Williams 2000)

Autorefractors

10. The Retinomax, a handheld automated refractor, had similar results with and without the use of cycloplegia to detect astigmatism (Cordonnier 1999).

11. The Retinomax has reliable results when detecting astigmatism, but it is unclear how well it will detect other condition (Cordonnier 1999).

Assessment: Vision Screening Tests and Programs

Random Dot E Stereotest (RDE)

1. The RDE can be used as an indicator of binocular vision status in preverbal children as young as 6 months of age (Schmidt 1994).

2. The RDE is a relatively good predictor when the results are normal (Hope 1990, Schmidt 1994).

3. Children who have a normal response on the RDE have a high likelihood of having:
   - Good visual acuity
   - Good eye alignment (no strabismus)
   - Good binocularity
   - Equally good vision in both eyes (no amblyopia) (Hope 1990, Schmidt 1994)

4. The RDE will not identify some children with poor vision (Hope 1990, Schmidt 1994).

5. Children with very low birth weight have increased risk for vision impairments (Darlow 1997).

6. For very low birth weight children, the presence of retinopathy of prematurity increases the risk by 2 to 3 times of having visual disorders (Darlow 1997).

7. The severity rating of retinopathy of prematurity makes a significant difference in vision outcome (Darlow 1997).

8. Astigmatism of ≥2 diopters is a predictor or risk factor for amblyopia (Abrahamsson 1990).

9. The tumbling E letter matching chart (HOTV) may not be practical for a widespread screening program because:

    • It requires a great deal of expertise

    • It requires follow-up because as a single test it is highly unreliable (Marsh-Tootle 1994)

10. The Modified Clinical Technique (MCT) had sensitivities ranging from 48% to 53% and specificities ranging from 77% to 79%. The generalizability of these results to children ≤3 years of age is uncertain since most of the children from the study ranged from 4 to 5 years of age and only 17% were <4 years of age (Marsh-Tootle 1994).

11. The Oxford County Screening Program, with sensitivities for predicting vision status varying from 60% to 70% and specificity varying from 70% to 80%, was based on a sample of children ranging in age from 37 to 75 months of age and therefore may be less applicable to children under 3 years of age (Robinson 1999).

12. In the community screening program, which included parent observation, the following questions are useful as indicators of poor vision:

    • Do the parents think the child sees normally?

    • Do the parents think the child's eyes look normal? (Johnson 1989)

13. In the community screening program that included parent observation, asking a question about whether the baby can pick up small objects does not appear to be a useful indicator of either good or poor vision (Johnson 1989).

Assessment: Assessment Tests and Techniques to Assess Visual Function

Teller acuity cards (TAC)

1. The TAC is most accurate in assessing vision acuity and identifying vision impairments in young children who:

    • Test as normal or blind (Dobson 1999, Mash 1998)

- Are as young as 4 months of age (Mash 1998)
- Are considered at risk for vision impairments (Hall 2000)

2. TAC does not accurately identify vision impairments in young children who:
   - Have neurodevelopmental delays (Dobson 1999)
   - Have abnormal vision (Hall 2000, Mash 1998)
   - Are from a general population cohort (Hall 2000)

3. TAC, when used to measure acuity in young children:
   - Has a high sensitivity and predictive value for identifying children with normal vision (Hall 2000, Mash 1998)
   - Is less sensitive in identifying children with abnormal vision (Hall 2000, Mash 1998)
   - Is less accurate than the Snellen letter charts (Mash 1998)

Other tests

4. The monocular and binocular grating acuity had high specificities but low sensitivities when compared with the monocular/binocular grating norms (Birch 1988).

5. The interocular grating acuity difference test had high sensitivities when compared with:
   - Normal range of interocular differences
   - Range of test-retest differences (Birch 1988)

6. The Preferential Looking Procedure can be useful in assessing the monocular grating acuity in preverbal children (Birch 1988).

7. The Parsons Visual Acuity Test (PVAT) had the highest sensitivity (85%) when using a cutoff score of 20/40 or worse for abnormal vision, and the highest range of specificities (89% to 91%) using a cutoff score of 20/60 or worse (Cibis 1985).

8. The Parsons Visual Acuity Test (PVAT) is an assessment test that is both obsolete and time-consuming to administer (Cibis 1985).

9. A normal visual evoked potential (VEP) is a good predictor of normal neuromotor outcome and abnormal results are not necessarily predictive of a poor prognosis (Mercuri 1999).

10. Absence of optokinetic nystagmus (OKN) at 6 months of age is a clinical clue of poor vision and neurodevelopmental outcome (Mercuri 1999).

11. Failing three parts of the Atkinson Battery of Child Development for Examining Functional Vision (ABCDEFV) administered at 5 months of age is predictive of poor neurological outcome at 2 years (Mercuri 1999).

12. Significant abnormalities on the vision exam at 5 months of age (particularly an abnormal optokinetic nystagmus (OKN) and very poor acuity) are predictive of poor neurodevelopmental outcome at the age of 2 years for children who have brain injuries (Mercuri 1999).

13. Although the Sheridan-Gardiner single optotype test of vision acuity identifies most children with amblyopia, it is most useful when administered in conjunction with other screening tests because:

    • Other screening tests prevent false negatives and therefore more children with vision impairment, such as amblyopia, are accurately identified

    • When the test is administered in isolation, some children with amblyopia are not accurately identified (Newman 1999)

Assessment: Neuroimaging and Electrophysiologic Measures

1. MRIs performed in infants with a history of hypoxic ischaemic encephalopathy or abnormal neurological signs predicts visual acuity with varying sensitivities and specificities depending on the location of the abnormality:

    • Basal ganglion – sensitivity of 72% and specificity of 100%

    • Occipital cortex – sensitivity of 67% and specificity of 79%

    • Either basal ganglion or occipital cortex – sensitivity of 100% and specificity of 79% (Mercuri 1997)

2. MRIs performed in infants with severe periventricular leukomalacia, predicts visual impairments based on:

    • Visual cortex findings – sensitivity of 15% and specificity of 100%

    • Optic radiation/visual outcome – sensitivity of 69% and specificity of 82% (Cioni 1997)

3. A large percentage (44.8%) of children with low birth weight and brain lesions documented by neuroimaging in the newborn period have strabismus by 2 years of age (Pinto-Martin 1996).

4. Children with low birth weight (<2000gms.) and abnormal neuroimaging with brain lesions and low Apgar (<5) scores have increased probability of vision impairments, specifically low vision (Pinto-Martin 1996).

5. Children with neuroimaging evidence of brain lesions who later develop cerebral palsy (CP) are at high risk for visual impairments, specifically low vision (Pinto-Martin 1996).

Intervention Approaches

Promoting general development

1. It is unclear, because of a large dropout rate and other study limitations, whether children who receive vision training intervention perform better in tracking, looking, and "reaching and looking for familiar objects" than do children who do not receive vision training (Sonksen 1991).

2. There appeared to be no significant differences in child outcomes between high- and low-intensity programs when working with young children with vision impairment (Behl 1993).

3. Family support, in addition to direct services to the child, is an important component of an intervention program (Behl 1993).

Teaching motor skills, orientation and mobility

4. Structured behavioral approaches are effective for teaching mobility and other skills to vision-impaired children with multiple disabilities (Harley 1987).

5. Applied behavioral analysis (ABA) that utilizes the graduated prompting response procedure can be an effective method for teaching specific motor behaviors and other skills to children with the coexisting disabilities of vision impairments and severe developmental delay (Correa 1984).

Vision stimulation

6. Because of incomplete data and other study limitations, it is unclear whether a vision stimulation program using artificial stimuli such as slides in infancy creates functional or physiological improvements in vision (Leguire 1992).

7. A stimulating natural environment for infants with vision impairment may help their overall development and encourage the functional use of vision (Leguire 1992).

Parent participation

8. There appeared to be no difference in child outcomes when parents are trained individually in the home versus in a group setting (Behl 1993).

9. There appeared to be no significant differences in child outcomes between child-parent focused interventions and interventions directed at parents when working with young children (Behl 1993).

10. Parents may express similar levels of satisfaction with both high- and low-intensity interventions (Behl 1993).

11. Parents are able to effectively implement an intervention program based on a criterion referenced assessment/curriculum in the home (Harley 1987).

12. The use of training materials and a curriculum can be helpful for parents working with their children in the home (Harley 1987).

Developmental Characteristics

Language and motor development

1. Children with visual acuities of 20/70 or worse in the best eye (with correction) have:
    *   The greatest delays in the motor domain followed by adaptive, cognitive, personal-social, and communication domains
    *   Higher communication scores, especially in the low acuity group in which no adaptations for vision were made (Hatton 1997)

2. Lower acuity scores are associated with:
    *   Greater motor delays
    *   Slower gains in personal-social development (Hatton 1997)

3. Significant drops in developmental scores for children with visual acuities of 20/800 may be indicative of the level of vision, possibly between 20/500 to 20/800, necessary for recognizing facial features, making eye contact, and recognizing nonverbal social cues in order to facilitate a response and an interaction (Hatton 1997).

4. When compared with children who have no vision, children with visual acuities of 20/800 vary little in developmental outcomes. Similarly, children with visual acuities of 20/799 to 20/70 vary little in developmental outcomes (Hatton 1997).

5. Children with vision impairment and children with blindness are two different samples developmentally and may have different patterns of development (Hatton 1997).

6. Blind children experience delays in all areas of motor development when compared with standard milestone tables for children who are sighted (Levitzion-Korach 2000).

7. Because of incomplete data and other study limitations, it is difficult to draw conclusions about the findings of lower auditory, language, and verbal ability quotient scores exhibited by blind children compared to normally sighted children (Parsons 1985).

Play patterns and behaviors

8. Children with low vision, ranging from 2 to 4 years of age, have the following similarities in play behaviors and patterns when compared to normally sighted children of the same age:
   - Functional play behavior increases
   - Total active play increases
   - The number of different appropriate uses of toys increases
   - Stereotypical play diminishes (Parsons 1986)

9. Children with low vision, ranging from 2 to 4 years of age, have the following quantitative differences in play behaviors and patterns when compared to normally sighted children of the same age:
   - Less functional use of toys
   - More stereotypical play (Parsons 1986)

10. Children who ranged in age from 4 to 48 months (adjusted for prematurity for children <2 years of age), when compared to partially age-matched (up to 48 months) normally sighted children, had significant differences on all levels of play (e.g., body-related, relational) and significantly higher variance in the mean age of individual levels of play (Troester 1994).

Sleep patterns and disorders

11. Children who are blind experience different behaviors and sleep patterns at bedtime compared with children who are sighted. Children who are blind tend to:
   - Experience more settling problems
   - Fall asleep later at night
   - Stay awake for longer periods during the night
   - Experience less total sleep time (Mindell 1997, Troester 1996)

12. Because of incomplete data (low parent response and parental classification of impairments), it is unclear whether children who are blind with single or multiple disabilities have significantly more sleep disorders compared to children who are partially sighted (Troester 1996).

13. It is unclear, because of incomplete data (low parent response and parental classification of impairments), whether children with partial sight and multiple disabilities have a higher prevalence of sleep disorders when compared to children who are blind (Troester 1996).

REFERENCE LIST

This reference list is limited for the purpose of this *Quick Reference Guide*. The complete Bibliography can be found in the *Report of the Recommendations* and the *Technical Report* versions of this guideline. First author in bold indicates that the article met the criteria for evidence for this guideline.

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SUBJECT INDEX

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GUIDELINE VERSIONS

There are three versions of each clinical practice guideline published by the Department of Health. All versions of the guideline contain the same basic recommendations specific to the assessment and intervention methods evaluated by the guideline panel, but with different levels of detail describing the methods and the evidence that supports the recommendations.

The three versions are

THE CLINICAL PRACTICE GUIDELINE:

Quick Reference Guide

- summary of major recommendations
- summary of background information

Report of the Recommendations

- full text of all the recommendations
- background information
- summary of the supporting evidence

The Guideline Technical Report

- full text of all the recommendations
- background information
- full report of the research process and the evidence reviewed

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