#### **CLINICAL PRACTICE GUIDELINE**

## REPORT OF THE RECOMMENDATIONS

## **VISION IMPAIRMENT**

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

# SPONSORED BY NEW YORK STATE DEPARTMENT OF HEALTH DIVISION OF FAMILY HEALTH BUREAU OF EARLY INTERVENTION

This guideline was developed by an independent panel of professionals and parents sponsored by the New York State Department of Health. The recommendations presented in this document have been developed by the panel, and do not necessarily represent the position of the Department of Health.

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### **Table of Contents**

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

Preface	xv
Why the Bureau of Early Intervention Is Developing Guidelines	xv
Overview of the Early Intervention Program	xvi
Chapter I: Introduction	1
Purpose of This Clinical Practice Guideline	2
Reasons for Developing This Guideline	3
Scope of the Guideline	3
Definitions of Common Terms	5
The Importance of Using Scientific Evidence to Help Shape Practice	6
Overview of the Methods Used to Evaluate the Evidence	7
Strength of Evidence Ratings	8
Using Scientific Evidence as the Basis for Clinical Decisions	10
The Peer Review Process	12
Guideline Versions	12
Chapter II: Background Information	15
What Is Vision? How Does the Eye Work?	16
What Is Normal Vision?	17
What Is Vision Impairment?	20
What Causes Vision Impairment?	23
What Is the Impact of Vision Impairment on Development?	26
How Is Vision Impairment Identified?	28
What Are Common Interventions for Children With Vision Impairment?	29
Who Are Vision Care Professionals?	31
Chapter III: Assessment	33
Identification and Assessment of Young Children With Vision Impairment	34
General Approach for Identification and Assessment	35
Identifying Young Children With Vision Impairment	40
Assessment of Visual Status	57
Developmental Assessment	67

#### TABLE OF CONTENTS

Assessing Orienta	ition and Mobility	93
Assessing the Ne	ed for Assistive Technology Devices	96
Working With the	Family	101
Chapter IV: In	ervention	113
Intervention Metho	ods for Young Children With Vision Impairment	114
General Approach	1	115
Medical and Surg	cal Interventions to Improve Vision	134
Interventions Foci	used on Improving Visual Function	143
Orientation and M	obility Training Interventions	148
Interventions for S	Specific Developmental Domains	153
Assistive Technol	ogy (AT)	174
Alternative Interve	ntion Approaches	179
	List of Appendices	
Appendix A:	Methodology Tables	183
Appendix B:	Summary of Evidence	193
Appendix C:	Developmental Assessment Tests	209
Appendix D:	Early Intervention Program Information	221
	D-1: Early Intervention Program Description	
	D-2: Official Early Intervention Program Definitions	
	D-3: Telephone Numbers for Municipal Early Intervention Programs	234
Appendix E:	Additional Resources	237
Appendix F:	Peer Reviewers	241
Bibliography		245
Subject Index.		259

#### **List of Tables** Table 1: Levels of Severity of Vision Impairments ......4 Table 2: Approximate Near-Vision Visual Acuity Equivalents ......18 Table 3: Development of Normal Visual Acuity......19 Table 4: Levels of Severity of Vision Impairments ......22 Table 5: Table 6: Ocular and Visual Disorders (Eye Conditions)......25 Risk Factors for Vision Impairment in Young Children......42 Table 7: Table 8a: Clinical Clues of Possible Vision Impairment in Young Children: Physical Exam Table 8b: Clinical Clues of Possible Vision Impairment in Young Children: Visual Table 8c: Clinical Clues of Possible Vision Impairment in Young Children: Visual Developmental Milestones ......45 General Vision Surveillance: The Physical Examination......48 Table 9: Table 10: General Vision Surveillance: Tests of Vision......49 Table 11: Components of the Basic Ophthalmic Exam......59 Table 13: General Components of a Visual Function Assessment.......65 Table 14: General Developmental Assessment Tests ......72 Table 15: Components of a Motor Assessment ......82 Table 16: Motor Milestones for Children With Severe Visual Impairment......84 Important Components of the Communication Assessment ......87 Questions to Ask When Evaluating Assistive Technology ......99 Table 20: Questions to Ask When Selecting Intervention Service Providers......127 Table 21: The Cultural Context of the Family: Influence of Family Beliefs and Values....131 Table 23: Examples of Vision Stimulation Activities.......147 Orientation and Mobility Training......150 Table 24: Table 25: Basic Principles of Child Development and Learning/Learning Theories ...... 158

#### TABLE OF CONTENTS

Table 26.	Considerations for Promoting Exploration of the Environment for Young Children With Vision Impairment158
Table 27:	Important Characteristics of Play Items for Young Children With Vision Impairment159
Table 28:	Age-Specific Approaches: Cognitive Interventions
Table 29:	Age-Specific Approaches: Sensory and Motor Interventions
Table 30:	Age-Specific Approaches: Communication Interventions167
Table 31:	Techniques for Developing Mealtime and Eating Skills170
Table 32:	Techniques for Developing Sleep Patterns171
Table 33	Age-Specific Approaches: Social/Emotional Interventions173
Table 34	Examples of Assistive Devices for Young Children With Vision Impairment175
	List of Methodology Tables
Table A-	: General Criteria for Selecting Evidence Studies185
Table A-2	2: Criteria for Adequate Evidence: Assessment Studies186
Table A-3	3: Interpreting Sensitivity and Specificity187
Table A-4	1: Criteria for Adequate Evidence: Intervention Methods
Table A-5	: Criteria for Adequate Evidence: Studies Providing Information About Developmental Characteristics190
Table A-6	: Strength of Evidence Ratings for Guideline Recommendations191
-	List of Figures
Figure 1:	Structure of the Eye
_	nental Assessment Tests: Types of Tests71
•	••

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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.

MICHAEL J. GURALNICK, Ph.D. University of Washington

## 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 for these guidelines was established by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Health Care 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 was also established to advise the department on this initiative. A national advisory group of experts in early intervention has been available to the department to review and to 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 either 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 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 families, to determine eligibility.
- Individualized Family Service Plans (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 those infants and toddlers whose healthy development is compromised, and provide for appropriate intervention to improve child and family development. The program's 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 needed by and 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 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 Department of Health 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 municipalities and service providers to enable them to identify, locate, and evaluate eligible children; developing individualized family service plans; 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.



## 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	RDE	Random Dot E Stereotest
CAT/CT	Computerized Axial Tomography	ROP	Retinopathy of prematurity
CP	Cerebral Palsy	RP	Retinitis pigmentosa
CPD	Cycles per degree	RT	Rehabilitation teaching specialists
CVI	Cortical visual impairment	TAC	Teller acuity cards
EI	Early Intervention Program	TVI	Teacher of the visually impaired
EIO	Early Intervention Official	VEP	Visual evoked potential
ERG	Electroretinogram	VER	Visual evoked response
HOTV	Tumbling E visual acuity eye chart	VLBW	Very low birth weight
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		

### CLINICAL PRACTICE GUIDELINE

## REPORT OF THE RECOMMENDATIONS

## **VISION IMPAIRMENT**

ASSESSMENT AND INTERVENTION FOR YOUNG CHILDREN (AGE 0-3 YEARS) This Clinical Practice Guideline: Report of the Recommendations presents the full text of all the recommendations, plus an abbreviated description of the methodology and evidence used to develop the recommendations.

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.

An abbreviated version of the background information and guideline recommendations can be found in Clinical Practice Guideline: Quick Reference Guide.

## CHAPTER I: INTRODUCTION

#### PURPOSE OF THIS CLINICAL PRACTICE GUIDELINE

This Report of the Recommendations guideline is based on Clinical Practice Guideline Technical Report that was developed by an independent, multidisciplinary panel of clinicians and parents convened 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 key elements of the guideline development approach include:

- Ensuring multidisciplinary representation
- Developing a guideline that is valid, objective, and credible
- Using a process that includes a combination of systematic review of the available scientific literature and expert clinical opinion

This guideline represents the guideline panel's concerted attempt to find and interpret the available scientific evidence in a systematic and unbiased fashion. It is hoped that by using an evidence-based approach, the guideline provides a set of recommendations that reflect current best practices and will lead to optimal outcomes for children and their families.

#### The guideline recommendations suggest "best practices," not policy or regulation.

The recommendations in this guideline are not intended to be regulations for the Early Intervention Program administered by the State of New York.

The guideline is intended as a set of recommendations that provide guidance about "best practices." **The guideline is not a required standard of practice**, and it should not be interpreted as policy or regulation. The guideline document is a tool that can be used to help providers and families make informed decisions within the context of the administrative system in which the care is being delivered.

Practitioners and families are encouraged to use the information provided in this guideline, recognizing that **the care provided should always be tailored to the individual.** Not all of the recommendations will be appropriate for use in all circumstances. The decision to adopt any particular recommendation must be made by the practitioner and the family in light of available resources and circumstances presented by individual children and their families.

#### **REASONS FOR DEVELOPING THIS GUIDELINE**

The goals of 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

#### SCOPE OF THE 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 1) that determines the extent of functional impact on the individual. For this guideline, the primary focus of the recommendations is children with vision impairments that are not correctable to at least the moderate low vision, regardless of etiology.

Table 1: Levels of Severity of Vision Impairments		
Level of Severity	Best Correctable Snellen Acuity Equivalent	
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)	

<sup>1</sup>Note: These definitions apply to adult levels of visual acuity Adapted from: ICD-9 Manual 1998

While moderate low vision is generally defined in terms of visual acuity (see Chapter II, page 15), 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 (Olson, 1987).

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.

#### **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.

Any provider of a professional service who is qualified by training, Professional

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 Children from birth to age 3 years.with visual impairment **Population** 

Throughout this document, the term young children is used to

describe this target age group.

Vision (or visual) impairment generally refers to any visual Vision

impairment that is not correctable to better than moderate low

vision, regardless of etiology.

**Impairment** 

Young Children Used broadly to describe the target age group for 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 D, "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 D)

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

## THE IMPORTANCE OF USING SCIENTIFIC EVIDENCE TO HELP SHAPE PRACTICE

Every professional discipline today is being called upon to document effectiveness. Professionals are increasingly asked to document that the approach used is effective in bringing about the desired outcomes. Those providing, receiving, or paying for services often want to know if there are other approaches, or modifications of existing approaches, that might produce better outcomes or similar outcomes at less cost. The difficulty in answering these questions is that many times the effectiveness of the methods used in current professional practice has not been studied extensively or rigorously.

Strengths of the evidence-based approach

Guidelines based on a review and evaluation of the scientific literature can help professionals, parents, and others learn what scientific evidence exists about the effectiveness of specific clinical methods. This approach provides parents and professionals from a variety of disciplines with information to make recommendations based on scientific evidence rather than based on opinion. When adequate scientific evidence can be found and systematically evaluated, it provides a balanced and objective approach for making informed decisions about intervention and assessment options.

Another strength of the evidence-based approach is that when evidence is sought but not found, it provides strong support for developing research agendas.

#### Limitations of the evidence-based approach

In general, the most significant limitation to using an evidence-based approach is that there may be a lack of adequate evidence specific to the topic of interest. For this guideline, many articles were found related to the guideline topic, but few articles met the guideline development panel's minimum criteria for study quality. Approximately 6,300 abstracts were screened for this guideline, and from these, over 500 articles were reviewed to determine whether they met the criteria for evidence. For many areas of interest (particularly regarding intervention methods), few or no studies were found that met the minimum criteria.

The panel recognized that there are numerous articles in the scientific literature that did not meet criteria for adequate evidence about efficacy, yet still contain valuable information. This would include articles that are case reports and case series (sometimes using pretest and posttest designs), as well as articles that primarily discuss theory or opinion. Although such articles often provide valuable insights that may be useful in clinical practice, these articles cannot provide adequate evidence about the efficacy of specific clinical assessment or intervention methods.

## OVERVIEW OF THE METHODS USED TO EVALUATE THE EVIDENCE

This clinical practice guideline for young children with vision impairment is part of a series of clinical practice guidelines being developed by the New York State Department of Health (NYSDOH) for assessment and intervention for young children with developmental disabilities. To develop these guidelines, the NYSDOH has chosen to use a methodology similar to that used by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Health Care Policy and Research (AHCPR), a part of the United States Public Health Service.

Using the AHCPR methodology, a multidisciplinary panel of topic experts, general providers (both clinicians and educators), and parents of children with vision impairment participated in a series of meetings to review the available research and develop guideline recommendations. In selecting panel members, the NYSDOH attempted to achieve a reasonable representation from the various disciplines involved in the care of children with vision impairment.

Scope of the guideline

The scope of this clinical practice guideline is to provide background information and specific recommendations related to identification, assessment, and intervention approaches for young children (birth to age three) with vision impairment. While the term vision (or visual) impairment can be broadly used to include a wide variety of conditions and levels of severity, the primary focus of this guideline is generally limited to children with vision impairment that is not correctable to better than moderate low vision, regardless of etiology.

After determining the general scope of the guideline, the guideline panel determined the specific topics and methods to be addressed, and which of those topics and methods were most appropriate for the focus of the literature search and review of evidence process. The panel chose to focus part of its examination of the scientific literature on developmental characteristics of young children with vision impairment.

Not all of the topics included in the guideline were appropriate for the review of evidence process. Some topics or methods were determined to be important to address with recommendations, but a specific literature search and evaluation of the evidence was not conducted.

In general, a literature search and review of the evidence were not conducted when:

- The topic or method, such as specific medical interventions, was not a primary focus of this guideline
- The literature was generally not specific to children with vision impairment and/or generally not considered controversial, such as providing appropriate developmental and health surveillance
- The topic was generally not the subject of scientific study, such as the importance of multidisciplinary team collaboration

#### STRENGTH OF EVIDENCE RATINGS

Each guideline recommendation has been given a "strength of evidence" rating, which is designated by the letter [A], [B], [C], [D1], or [D2] in brackets immediately after the recommendation. The strength of evidence rating indicates the amount, general quality, and clinical applicability (to the guideline topic) of scientific evidence the panel used as the basis for that specific guideline recommendation.

- [A] = Strong evidence is defined as evidence from two or more studies that met criteria for adequate evidence that were considered to have high quality/applicability for this guideline.
- [B] = Moderate evidence is defined as evidence from one study that met criteria for adequate evidence that was considered to have high quality/applicability for this guideline.
- [C] = **Limited evidence** is defined as evidence from one or more studies that met criteria for adequate evidence that were considered to have intermediate quality/applicability for this guideline.
- [D] = **Panel consensus opinion** (either [D1] or [D2] below):
  - [D1] = **Panel consensus opinion** based on information not meeting criteria for adequate evidence about efficacy, on topics for which a systematic review of the literature was conducted
  - [D2] = **Panel consensus opinion** on topics for which a systematic literature review was not conducted

Recommendations based on information from studies about the developmental characteristics of young children with vision impairment are given Evidence Ratings noted with a [dc] following the Evidence Rating.

The methodology for determining adequate evidence is summarized in Appendix A.

There were two situations when panel consensus opinion was used as the basis for recommendations:

- A [D1] strength of evidence rating was used when a systematic review of the scientific literature was conducted for a topic, but no adequate evidence was found.
- A [D2] strength of evidence rating was used for all recommendations on topics for which the panel did not do a systematic literature review because they were either outside the primary scope of the guideline or not usually subjected to scientific study. For some topics with this rating, adequate scientific evidence may exist, but if the topic was outside the primary scope of the guideline, the literature was not reviewed.

A strength of evidence rating indicates the *type of information* used as the basis for the recommendation. The strength of evidence rating does not reflect the importance of the recommendation or its direction (whether it is a recommendation for or against use). For example:

- If there was strong evidence that an intervention is effective, then a recommendation for use of the method would have an [A] evidence rating.
- If there was strong evidence that an intervention is not effective, then a
  recommendation against use of the method would also have an [A]
  evidence rating.

All recommendations on topics where a systematic literature review was conducted were considered to be "evidence-based" recommendations. Therefore, even if the literature review for a topic found no studies that met criteria for adequate evidence, recommendations about that topic were still considered evidence-based.

## USING SCIENTIFIC EVIDENCE AS THE BASIS FOR CLINICAL DECISIONS

Considerations about using scientific evidence

In developing evidence-based clinical practice guidelines, the process of reviewing the scientific literature to find evidence-based answers to specific clinical questions is challenging. Many times, the specific clinical issue of interest may not have been studied extensively in well-designed studies of the type that can adequately determine if a clinical method is effective. At other times, even when well-designed studies have been conducted on a particular clinical topic, the study findings themselves seldom present totally straightforward and unambiguous answers to the clinical questions of interest. Careful analysis of the studies and considerable judgment are always needed when using the findings of research studies to help in making informed clinical decisions and developing clinical practice guidelines.

In developing practice guidelines for most clinical topics, it is uncommon to find studies that evaluate exactly the clinical situations and types of subjects that are of interest. Therefore, it is almost always necessary to generalize to some extent in terms of the subject characteristics (such as age or IQ) and the clinical setting or the type of assessment or intervention method used. The research reviewed for this guideline was no exception.

In using research evidence to help make clinical decisions, the two primary considerations are the *quality* of the evidence and its clinical *applicability* to the question of interest.

 The quality of the study is primarily related to the study design and controls for bias; the higher the quality of the study, the more confidence we can have that the findings of the study are valid. Confidence in the study findings becomes even greater when multiple well-designed studies conducted by independent researchers find similar results.

The clinical applicability of a study is the extent to which the study's results would also be expected to occur in the particular clinical situation of interest. The applicability of a study's findings is considered to be higher when the subject characteristics, clinical methods, and clinical setting are similar between the study and clinical situation of interest.

The overall usefulness of a study's findings to clinical decision making relates both to confidence in the results (based on the quality and amount of scientific evidence) and the similarity of the study's subjects, clinical methods, and setting to the question of interest (i.e., its applicability).

Criteria for studies used in developing this guideline

For this guideline, the guideline panel chose to:

- Adhere to relatively rigorous criteria for selecting studies as providing high quality evidence about efficacy
- Distinguish between high quality/applicability and intermediate quality/applicability for intervention studies
- Supplement efficacy articles with descriptive articles meeting criteria for evidence about developmental characteristics

Findings from studies meeting the criteria for evidence (either efficacy or developmental characteristics) were used as the primary basis for developing the evidence-based guideline recommendations. The criteria for evidence are defined in the methodology tables found in Appendix A.

In many cases, information from other articles and studies not meeting the evidence criteria was used by the panel, but information from these sources was not considered evidence about efficacy and was not given as much weight in making guideline recommendations.

Descriptive evidence taken from studies on developmental characteristics was used to make inferences about what assessment and intervention methods might work best for children with vision impairment. This type of evidence can be useful in clinical decision making, although findings of descriptive articles do not provide evidence as strong as the results of the efficacy studies do.

Considerations about applicability of studies

Of particular concern for this guideline was finding scientific studies that focused on the target population, children younger than age three. For some topics, studies were found that evaluated only children within the guideline's target population (children from birth to 3 years of age), but for other topics the only studies found evaluated groups that included somewhat older children (older than age three).

As noted above, having a study with children older than age three does not affect the quality of the study or bias the results, but it may make the study's findings somewhat less applicable to the guideline topic. The panel considered this when making guideline recommendations, and generally gave more weight to findings from studies that focused on children younger than 3 years old. However, when few good studies were found that focused on children in the target age group, the panel thought it important to generalize from evidence found in good studies of somewhat older children.

Judging the quality and applicability of the evidence when making guideline recommendations

Because of the considerations above, the panel needed to use significant judgment in evaluating the quality and applicability of the scientific evidence when using it as the basis for the evidence-based recommendations. Similar limitations and considerations apply to all evidence-based practice guidelines. The strength of evidence ratings are a reflection of both the amount and quality of the scientific evidence found and its applicability to the guideline topic.

#### THE PEER REVIEW PROCESS

The draft guideline was sent to a variety of topic experts, generalist providers, and parents for peer review. Comments on the draft document were solicited, and the panel reviewed these comments before making final revisions in the guideline. Review comments were received from 50 external reviewers.

### **GUIDELINE VERSIONS**

There are three versions of this clinical practice guideline published by the New York State Department of Health. All versions of a guideline contain the same basic recommendations specific to the assessment and intervention methods evaluated by the panel, but with different levels of detail describing the literature review methods and evidence that support the recommendations.

- Clinical Practice Guideline: The Guideline Technical Report
   Includes the full text of the recommendations and related background information, plus a full report of the research process and evidence that was reviewed.
- Clinical Practice Guideline: Report of the Recommendations
   Includes the full text of all the recommendations and related background information and a summary of the research methodology.
- Clinical Practice Guideline: The Quick Reference Guide
   Provides a summarized version of the guideline recommendations and background information.

# Periodic Review and Revision of the Guideline

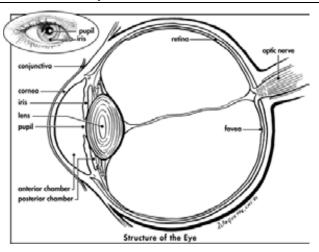
It is intended that this NYSDOH Clinical Practice Guideline on vision impairment in children from birth to age three be a dynamic document that is updated periodically as new scientific information becomes available. This guideline reflects the state of knowledge at the time of development, but given the inevitable evolution of scientific information and technology, it is the intention of the NYSDOH that periodic review, updating, and revision will be incorporated into an ongoing guideline development process.

# CHAPTER II: BACKGROUND INFORMATION

#### WHAT IS VISION? HOW DOES THE EYE WORK?

Vision occurs when images (visual stimuli) are received by the eye and transmitted to the brain. Vision is a complex process that involves the eye, the brain, and the pathways between them. The eye is somewhat similar to a video camera connected to a computer. Just as a video camera has a shutter and a lens system that controls the light and focuses the image, the eye has a system that controls the amount of light allowed in and focuses light rays onto the back of the eye. This system includes the eyelids, cornea (a clear, dome-shaped window at the front of the eye), iris, pupil (controls the amount of light), and lens (focuses the image).

Figure 1: Structure of the Eye



The retina is located at the back of the eye and 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

When the retina is stimulated by light, this stimulation produces rapid electrophysiologic reactions, which are not totally understood. 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, that allow a person to fixate on the object and identify it. There are over 30 areas in the brain that are involved in receiving and translating visual stimuli.

#### Development of the visual system

Babies are born with the ability to see, but the visual system is not fully developed at birth. Maturation of the visual system occurs over several years and involves growth and organization all along the visual pathways, from the photoreceptors in the eye to the visual cortex in the brain. 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. The visual system remains somewhat responsive to changes in visual stimulation until the age of visual maturity (Olitsky 1998, Menacker 1993). 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 letter, numbers, or pictures are seen on a standardized eye chart (referred to as an optotype).

The first standardized eye chart designed to measure visual acuity was introduced by Herbert Snellen in 1862. Although the Snellen eye chart was introduced well over a hundred years ago, it is still the most common way to measure and report visual acuity.

The expression "20/20" refers to a person's visual acuity using the Snellen eye chart. This is the eye chart that is most commonly used for obtaining a general

measure of how well someone is able to discriminate visual images at different distances. The Snellen visual acuity rating is written as a fraction:

- The numerator (top number) is the testing distance, usually 20 feet (or 6 meters) but sometimes less for small children (10 feet or 3 meters)
- The denominator (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 20/30 vision can see clearly from 20 feet what a person with normal visual acuity is able to see at 30 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.

Table 2:	Appro	ximate N	Near-Vision	n Visua	l Acuity E	quivalents	
Snellen			Near	-Vision	Equivalents	S	
Distance Vision	Meters Equiv	Jaeger	AMA Notation	Point Size	Approx Height	Visual Angle	Text Size
20/20	0.4 M	_	14/14	3	.58mm	5.00	_
20/25	0.5 M	J1	14/17.5	4	.75mm	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	Ј9	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
	20.0 M llen measur n equivaler		14/700 e vision. The o	— ther meas	30.00mm surement value	250.00 es indicate the	1-inch lette

Sometimes, instead of a fraction, the decimal equivalent is used to report visual acuity results. In this reporting method, rather than designating the normal visual acuity as 20/20, it would be reported as 1.00. More recently, the logMAR notation (logarithmic minimum angle of resolution) has been used to express visual acuity and has gained international popularity.

#### 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, normal binocular (both eyes) visual development requires the brain 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 a full-term baby (Olitsky 1998, Menacker 1993). In at least one study of normal visual acuity using behavioral methods, acuity increased rapidly during the first six to eight months of life and then more slowly for the next two years (Chandna 1991). At 36 months, visual acuity is still developing (Adoh 1994, Chandna 1991).

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, page 18 describes the range of visual acuity scores on one acuity test for normally sighted children between 12 and 36 months of age. As with adults, slightly better visual acuity is achieved when children use both eyes. Visual acuity scores within two standard deviations from the mean are considered to be within the normal range.

Cardiff Acuity Test  Age Interval	Snellen Equivalent			
(Months)	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		

#### **CHAPTER II: BACKGROUND INFORMATION**

### 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 4, page 21).

#### 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 (Hatton 1997). Approximately 1 in every 3,000 infants is born with a severe vision impairment (Olson, 1987). However, because vision is the perceptual system 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: 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, e.g., 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

# Levels of severity of vision impairments

In one of the major medical classification systems, the *International Classification of Diseases* (ICD-9), the term "visual impairment" refers to a functional limitation of the eye (such as limited visual acuity or visual field) as distinguished from "visual disability" (a limitation of the abilities of the individual) and from "visual handicap" (a limitation of personal and socioeconomic independence). The existence of a "visual impairment" depends on one's frame of reference. Young children who have a best correctable visual acuity of 20/200 are not considered to have a visual impairment if what they normally do requires only that amount of vision. For example, a 3-year-old with 20/200 vision may be able to interact well with peers. However, by the time the child reaches first or second grade and is required to do tasks requiring attention to fine details, this acuity may become a visual impairment to the child.

Table 5: Levels of Severity of Vision Impairments			
Level of Severity	Best Correctable Snellen Acuity Equivalent <sup>1</sup>		
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 20/1,000		
Near total blindness	less than 20/1,000		
Total blindness	No light perception (NLP)		
<sup>1</sup> Note: These definitions apply to adu Adapted from: ICD-9 Manual 1998	lt levels of visual acuity.		

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. A visual acuity of 20/200 means that a person has to stand 20 feet from the eye chart in order to see what a person with normal vision would be able to see from 200 feet away.

The legal definition of blindness was created primarily for adults in order to determine eligibility for government assistance and rehabilitation (Gurland 1994). Many individuals who are legally blind have enough sight that they can read print at close range and use their vision for mobility purposes.

Sometimes, individuals are classified as legally blind not because of diminished visual acuity but because of restrictions in their visual field. A person can be classified as 'legally blind' because of visual field restrictions. However, visual field can be difficult to measure in young children and therefore 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 (Olson 1987). *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) than the child's visual acuity (Olson 1987).

Hatton (1997) views visual impairment as a continuum of decreasing visual function and suggests that two broad levels of visual function may be sufficient to describe developmentally different populations of children with vision impairment. These populations are:

- Children whose best correctable visual acuity ranges from 20/70 to 20/500 who are able to perform visual tasks, although perhaps not efficiently when compared to normally sighted children.
- Children whose best correctable visual acuity ranges from 20/800 to no light perception for whom available vision is unreliable and sufficient for gross visual tasks only.

Children whose best correctable visual acuity is 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. A cutoff somewhere between 20/500 and 20/800 separates these two populations.

### WHAT CAUSES VISION IMPAIRMENT?

Many different visual disorders can cause vision impairment. These disorders are sometimes generically referred to as "eye conditions" even though the problem may be within the eye or in the visual nervous system. The eyes of children with vision impairment will often appear normal to a casual observer.

A child's diminished ability to see may be related to a problem with one or more of the following processes:

- 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 and interpreting the 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

#### **CHAPTER II: BACKGROUND INFORMATION**

What are the most common causes of vision impairments?

Worldwide, the most common cause of vision impairment is ulceration of the cornea, secondary to vitamin A deficiency (Davidson 1997). This eye disorder is most prevalent in developing countries and is not addressed in this guideline. In the United States, the most common disorders of the visual system include cortical visual impairments, retinopathy of prematurity, optic nerve hypoplasia, and structural abnormalities (Ferrell 1998).

While there has been an increase in childhood visual impairment attributable to a genetic etiology in the past fifty 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 decline in the incidence of 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.

The increasing importance of genetic factors as a cause of childhood visual impairment is also due to increased recognition of factors contributing to retinopathy of prematurity and a subsequent decrease in the severity of related visual impairment. Finally, there is an increased understanding of many genetic diseases that can result in childhood visual impairment, such as genetic diseases of the retina (retinitis pigmentosa, retinoblastoma, Leber's congenital amaurosis), optic nerve (optic nerve atrophy, hypoplasia of the optic nerve), lens (congenital cataract, ectopia lentis), eyeball (albinism, congenital glaucoma, Marfan syndrome), and iris (aniridia, coloboma).

As a result of the increasing importance of genetic disorders and the continued decrease in acquired causes, the prevention of blindness and the care of children with childhood visual impairment requires increasing knowledge of genetic eye diseases and the provision of accurate genetic counseling.

# Table 6: 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 lens of the eye, its capsule, or both
- Cortical visual impairment (CVI) reduced vision due to cortical damage in one or more areas of the brain; is 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

Table 6 lists some of the eye conditions that can result in vision impairments. These different eye conditions are generally associated with different levels of visual function, and some may also be associated with more general central nervous system damage that can result in co-occurring disabilities such as mental retardation or cerebral palsy (Hatton 1997). These are divided into serious disorders that are likely to cause disabling impairment of vision and less serious disorders that lead to reduced visual acuity if not recognized and treated in time (Lennerstrand 1995).

# 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 is also an important factor in early interactions between the infant and the parent(s). Because interaction with the environment plays such a major role in typical development, 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 to typically developing children.

#### Overall development

The impact of vision impairment on children's overall development has been well documented by a recent longitudinal study of 186 children who have decreased visual acuities (Hatton 1997). The overall developmental consequences of vision impairment depend both on children's visual function and any co-occurring 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

A child's development of gross and fine motor skills is particularly affected by the lack of visual information (Hatton 1997, Levtzion-Korach 2000). Of all the developmental domains, the motor domain may be the most adversely affected by severely impaired visual function (Hatton 1997). Children who are severely visually impaired (even those without other impairments) tend to be delayed in all areas of motor development when compared with standard milestone tables or with children who are sighted (Levtzion-Korach 2000).

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 in the environment. If a child does not have enough functional vision to realize that a person or object is present, the child will have to learn to reach and move based on 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 is also delayed in children who have severely impaired visual function compared with children who have better vision (Hatton 1997). Early cognitive development and motor development are interrelated and can affect a child's ability to interact with objects and people in the environment.

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 (Olson 1987). Blind children's delay 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 (Hatton 1997, Parsons 1985). Communication development, at least as measured by the BDI, may be impacted less than the development in other domains (Hatton 1997). Many children with vision impairment acquire language within the same range as normally sighted children do (Hatton 1997).

However, communication involves more than just speaking and listening. Much of communication involves nonverbal cues, which are primarily visual. Visual cues are an important aspect of social interaction. Social interaction scores on the BDI are lower for children who have severely impaired visual function compared with children who have better vision (Hatton 1997).

A visual function of approximately 20/500 to 20/800 may be the amount of vision 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 children who are blind (Davidson 1997). Children who are blind play differently than normally sighted children play. 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 (Troester 1994).

Adaptive/self-help skills development

Adaptive/self-help skill development in young children generally 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 BDI are lower for children with severely impaired visual function than are scores for children with better vision (Hatton 1997).

#### HOW IS VISION IMPAIRMENT IDENTIFIED?

There are multiple ways that a child's suspected vision impairment may first be identified. These methods of detecting possible vision impairments are not designed to arrive at a formal diagnosis, but rather to identify children with an increased likelihood of vision impairment and who therefore need further assessment.

- For some children, risk factors for possible vision impairment may be identified at birth. Some of these risk factors include extreme prematurity and low birth weight, family history of blinding eye conditions, (e.g., infantile cataracts, retinoblastoma, infantile glaucoma, or hereditary corneal dystrophy), and maternal intrauterine infections (Table 7, page 42).
- For some children, 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.
- For still other children, vision impairment is detected because of parental concerns about the child's vision. 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 in fact have normal vision at the follow-up testing, it is hoped that implementation of screening 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 some 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 do not know the alphabet. Other versions of a visual acuity eye chart, such as one with pictures or with only the letter E facing different directions, are typically used for children younger than 5 years of age. Infants are usually tested using preferential looking techniques (page 60). Sometimes, electrophysiological procedures (page 63), primarily visual evoked procedures, are also used.

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, typical interventions generally 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 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 problems (Hatton 1997). Therefore, intervention is often focused on orientation and mobility, and on 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 has multiple purposes, with the overall goals of determining what interventions are indicated and establishing baseline information. Components of the assessment process usually include:

- Functional vision assessment of how the child uses vision to interact with the environment
- Assessment of the developmental impact of the vision impairment (cognition, motor development, communication, adaptive/self-help skills, and social interactions and play)
- Assessment of the child's orientation and mobility needs
- Health evaluation to determine whither the child has any associated health or developmental conditions, including hearing loss
- Learning media assessment to document which sensory functions the child uses 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 the environment (interaction 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.

Young children with severe visual impairments are often either reluctant or not motivated to move about and explore the environment. This lack of exploration can impact both motor and cognitive development. Other areas of development (communication, adaptive/self-help skills, and social interactions and play) are also affected because much of the learning of developmental skills usually occurs through exploration of the environment, observation, and modeling.

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. In a study by Hatton (1997), almost 40% of 186 children in the study who had visual impairment also had a diagnosis of mental retardation/developmental delay (MR/DD). An additional 18 children had vision impairment and some other developmental disability.

Assessment of the resources, priorities, and concerns of a child's family is especially important for young children with vision impairment. An assessment of the family's resources, priorities, and concerns is designed to help develop intervention plans that are meaningful and relevant to the family. Regardless of the interventions, parental involvement can help promote the developmental abilities of the child.

A family's needs change over time. At first, many families need information about vision impairments in general and their child's eye condition in particular. They may need information about how vision impairment can affect other areas of development (e.g., gross and fine motor development, cognition, communication, social interactions, and adaptive/self-help skills). Later, they may need information about specific strategies to help their child use residual vision or information about adapting the environment to enable their child to move about safely. Some families may have adequate informal support systems, whereas other families may desire support from professionals or other parents of children with vision impairment.

### WHO ARE VISION CARE PROFESSIONALS?

Vision care professionals who may be involved in the assessment and/or treatment of 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 prescribe topical medications (medications applied directly to the eye such as eye drops or ointments) for the treatment of some 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 impairment.

**Opticians** make glasses prescribed by an 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 (O&M) Specialists specialize in the instruction of safe and efficient independent travel skills for individuals with visions impairments. They assess a child'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 vision impairment 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.

**Note:** Other professionals (occupational and physical therapists, speech language pathologists) 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 OF YOUNG CHILDREN WITH VISION IMPAIRMENT

Vision is the process of receiving stimuli transmitted to the eye and then to the brain, and translating those stimuli into images. Because vision plays such an important role in a child's early development, identification of vision impairment in young children is especially important.

There are several basic aspects of vision, such as form perception (visual acuity), color perception, and motion perception. Vision impairment is the loss of some aspect of vision and can occur as the result of a problem at any point along the visual pathway. Some vision impairments may be easily corrected with glasses, surgery, or other medical intervention. Other vision impairments may not be correctable.

Evaluating the accuracy of identification and assessment methods

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. Using this broad definition, assessment methods include both 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.

An ideal identification or assessment method would be inexpensive, simple to administer, and highly accurate in differentiating children with a particular condition from those without the condition. Total blindness and severe vision impairment are usually relatively easy to identify by observation alone, but most other vision impairments are not always obvious. 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.

The accuracy of a particular identification or assessment method can be defined by determining its sensitivity and specificity.

The sensitivity of an assessment method is the percentage of all persons with the condition who have a positive test correctly identifying the condition (the true positive rate). A screening method with a high sensitivity does a good job identifying persons who have the condition. The higher the sensitivity of a screening method, the lower the false negative rate.

■ The **specificity** of an assessment method is the percentage of all persons who are correctly identified by the test as not having the condition. The specificity of a test is the percentage of all persons who do not have the condition who have negative test results (the true negative rate). A screening method with a high specificity does a good job identifying persons who do not have the condition. The higher the specificity of a screening method, the lower the false positive rate.

# Topics included in this chapter:

- General Approach for Identification and Assessment
- Identifying Young Children With Vision Impairment
- Assessment of Visual Status
- Developmental Assessment
- Assessing Orientation and Mobility
- Assessing the Need for Assistive Technology Devices
- Working With the Family

### GENERAL APPROACH FOR IDENTIFICATION AND ASSESSMENT

#### **Evidence Ratings:**

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

This section provides general recommendations related to identifying and assessing young children with vision impairment. Topics include the following:

- General Considerations for Identification and Assessment
- General Considerations for Professionals

Basis for the recommendations in this section

Recommendations about the general approach for the identification and assessment of young children with vision impairment are based primarily on panel consensus opinion. These recommendations address topics for which the literature was not specifically reviewed as a focus of this guideline. Some of the

recommendations are based on information from review articles that were considered by the panel in the absence of specific studies meeting the criteria for evidence. In the panel's opinion, these consensus recommendations reflect appropriate practices for assessing children with vision impairment and are generally consistent with the current knowledge in this field.

#### General Considerations for Identification and Assessment

When identifying and assessing young children with diagnosed or suspected vision impairments, some general principles can be applied. Many of these general principles are not unique to young children with vision impairment, but may be applied within a larger general model for assessment and intervention for all young children who have developmental disabilities.

# **Recommendations** (General Considerations for Identification and Assessment)

Importance of early identification and intervention

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It is important to identify children with vision impairment as early as
possible so that appropriate assessment and intervention can be initiated.
Early identification and appropriate intervention may help to maximize the
child's general development and may promote better long-term functional
outcomes.

[B] (Correa 1984, Hall 2000, Harley 1987, Ottar 1995) [C<sub>dc</sub>] (Levitzion-Korach 2000, Troester 1996)

**Early Intervention Policy**  Children with vision impairment and who meet the state definition are eligible for the Early Intervention Program. Professionals who suspect, because of parental concerns or results of developmental surveillance, that a child may have vision impairment, must refer the child to the Early Intervention Official unless the parent objects to the referral.

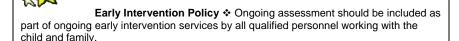
Identifying initial concerns about possible vision impairments

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, such as prematurity or perinatal problems
- A parent's or professional'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 possible vision impairment at the time of a periodic health exam or when the child is being evaluated for some other health or developmental concern [D2]

#### The assessment process

3. It is important that assessment be viewed not as a single event. After the initial assessment, it is important to have ongoing monitoring and periodic reassessment of the child's progress over time. [D2]



- 4. It is important to recognize that for children with vision impairment, information about a child's condition and prognosis is based on observations as well as diagnostic work-up. As such, it is especially important to:
  - Allow enough time to observe the child adequately
  - Take time to listen to the parents' observations of the child in other settings (e.g., home or child care settings) [D2]
- 5. It is important for those assessing the child to understand the whole child and consider any factors that may have an impact on the child's performance during the assessment process. For example:
  - The child's schedule
  - The child's overall health status and current environmental influences
  - The child's mood and temperament (fatigue, illness, shyness, excitement) at the time of assessment [D2]
- 6. It is recommended that assessment materials and strategies be developmentally appropriate. [D2]

- 7. It is recommended that the setting in which the assessment is performed:
  - Be appropriate to the developmental stage of the child
  - Be comfortable for both parent and child
  - Be in the child and family's natural environment when appropriate [D2]

#### **General Considerations for Professionals**

Infants with vision impairment often have delays in other developmental domains. 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 for these young children. This section includes general consideration recommendations for the professionals who work with these children and their families.

## **Recommendations (General Considerations for Professionals)**

Importance of understanding about vision impairment

- 1. It is important for health care professionals (such as physicians, nurses, therapists, or physician assistants) to understand typical visual development in young children in order to:
  - Facilitate recognition of potential vision problems
  - Facilitate the use of appropriate methods for ongoing monitoring (developmental surveillance)
  - Give accurate information to parents and families
  - Assist with making appropriate referrals [D2]
- 2. It is important that early childhood professionals (teachers, administrators, and paraprofessionals working in child care, preschool, and other settings) receive information about typical visual development in young children in order to:
  - Make appropriate observations about the child's development
  - Give accurate information to parents and families
  - Assist in making appropriate referrals
  - Facilitate appropriate intervention strategies [D2]

Assuring quality and consistency

3. 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 children with vision impairment as well as observational information
- Use procedures that are reproducible by other professionals [D2]

#### Important professional characteristics

- 4. It is important that professionals assessing young children be knowledgeable and experienced. Important characteristics include:
  - Having a solid understanding of typical newborn and early childhood development
  - Having a solid understanding of atypical patterns of development
  - Being an accurate and impartial observer
  - Having well-developed, active listening skills
  - Understanding the importance of the multidisciplinary approach
  - Recognizing cues from the child
  - Understanding the importance of being sensitive to parents and knowing how to work within their comfort zone
  - Being familiar and comfortable with the assessment tools and procedures so the focus is on the infant/child and parents, not on the assessment tool [D2]

#### Considering the cultural and family context

- 5. A child's life is embedded within a cultural and family context. A family's way of living is influenced by many factors, including its ethnic and cultural roots. When working with families, it is essential to consider:
  - The family's culture
  - Parent priorities
  - Parenting styles
  - Family support systems [D2]
- 6. When evaluating children with vision impairment, it is important to recognize that there may be cultural and familial differences that shape the family's expectations about things such as play and social interaction, pragmatic use of language in social context, and eye contact, and the development of adaptive or self-help skills and independence. [D2]

7. If English is not the primary language of the family, it is important for professionals to look for ways to communicate effectively with the family and the child. This includes finding professionals and/or translators/interpreters who speak the primary language of the child and the family, and whenever possible, those who are familiar with terminology related to vision impairment and to early intervention. [D2]

Early Intervention Policy ❖ The multidisciplinary evaluation must be performed using nondiscriminatory procedures as defined in program regulations (Appendix D) and be conducted in the child's dominant language whenever feasible.

#### IDENTIFYING YOUNG CHILDREN WITH VISION IMPAIRMENT

**Evidence Ratings:** 

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[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

Topics covered in this section:

- Risk Factors, Clinical Clues, and General Surveillance
- Screening for Amblyopia and Refractive Errors

Basis for the recommendations in this section

The recommendations for identifying young children with vision impairment are derived primarily from studies that met the criteria for evidence for this topic. Some parts of this section also include consensus recommendations based on information from review articles that were considered by the panel in the absence of specific studies meeting the criteria for evidence. Other consensus recommendations generally relate to approaches for which the literature was not specifically reviewed. In the panel's opinion, these recommendations reflect appropriate practices for assessing children with vision impairment and are generally consistent with scientific knowledge in this field.

### Risk Factors, Clinical Clues, and General Surveillance

The early identification of young children with vision impairment can occur in a variety of ways. In some cases, a child's suspected vision impairment may be identified at birth (if the child is premature or has other known risk factors for certain health or developmental problems). For other children, identification of the vision impairment may occur later because of parental concerns about the child's vision. Concern about the child's vision may develop also as the result of parental information about certain behaviors, lack of progress in the child's development, or as the result of direct observation of the child during routine health care visits.

# Risk factors and clinical clues

Risk factors and clinical clues may be used to heighten concern about a possible vision impairment. A *risk factor* is something that increases the possibility that the child will have vision impairment (Table 7, page 42). A *clinical clue* is a possible early sign or symptom of vision impairment (Tables 8a and 8b, pages 43-44). These may be noted by parents, professionals, or others interacting with the child.

The presence or absence of risk factors or clinical clues is not by itself enough to establish that vision impairment exists or does not exist. Risk factors and clinical clues for vision impairment are sometimes seen in children who do not have a vision disorder. The recognition of a risk factor or clinical clue merely provides an indication that further assessment may be needed.

#### Prematurity and very low birth weight as risk factors

One of the most commonly identified risk factors for vision impairment is prematurity. Retinopathy of prematurity is a well-documented and well-studied cause of vision impairment in young children who are born prematurely. 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.

The greatest risk for retinopathy of prematurity is in very premature infants with a very low birth weight. Although much has been learned in the past ten years about identifying and caring for infants at risk for ROP, efforts to reduce the incidence of ROP in high-risk infants have not been completely successful.

In the past, supplemental oxygen given to newborns was implicated as the cause of retinopathy of prematurity. It is now understood that many factors appear to contribute to the development of ROP, and although supplemental

oxygen is a risk factor for ROP, the precise contribution of oxygen levels to development of the condition is unclear. The intensity of the lights in the newborn nursery has not been shown to play a role in the development of ROP (Reynolds 1996).

While there are now well-accepted standard methods for identifying and treating retinopathy of prematurity (as well as many of the other conditions that are risk factors for vision impairment), a detailed discussion of the specific medical diagnostic procedures, the medical management of premature infants at risk for developing ROP, and the medical treatments for complications of ROP are beyond the primary scope of this guideline.

# Cortical visual impairment (CVI)

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 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.

# Table 7: Risk Factors for Vision Impairment in Young Children

Examples of 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 lower at 5 minutes), and brain lesion noted on imaging (Pinto-Martin)

#### **Congenital Conditions**

- Albinism
- Cerebral palsy
- Chromosomal abnormalities such as Down syndrome

# Table 7: Risk Factors for Vision Impairment in Young Children

#### 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 (Continued from previous page)

# Table 8a: Clinical Clues of Possible Vision Impairment in Young Children: 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 (APD)
- 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

# Table 8a: Clinical Clues of Possible Vision Impairment in Young Children: Physical Exam Findings

- 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 (Continued from previous page)

# Table 8b: Clinical Clues of Possible Vision Impairment in Young Children: Visual Behaviors

#### **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 8c: Clinical Clues of Possible Vision Impairment in Young Children: 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)

# Table 8c: Clinical Clues of Possible Vision Impairment in Young Children: Visual Developmental Milestones

- 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)

#### By 36 months:

- Smiles, face brightens when viewing 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)

# General surveillance for vision impairments

General health and developmental surveillance for vision impairment in infants and young children is usually conducted as a component of routine health care examinations beginning at birth. Surveillance is a term used to describe the approach practiced by health care providers for the early detection of a variety of health and developmental problems. Surveillance is a flexible, continuous process in which knowledgeable professionals monitor a child's health and developmental status, usually during the provision of health care services. The process of health and developmental surveillance includes eliciting and attending to parents' concerns, obtaining a relevant health and developmental history, observing children accurately, and sharing opinions and concerns with other relevant professionals.

The components of basic surveillance for vision impairment depend on the child's age. In general, surveillance for vision problems for infants and young children usually includes inspection of the eyes, tests for ocular motility and eye muscle imbalance, ophthalmoscopic examination, and tests for visual acuity as appropriate for the age of the child (American Academy of Pediatrics - AAP 1996). Surveillance for preschool children may also include an evaluation of stereoacuity and color vision.

## Recommendations (Risk Factors, Clinical Clues, and General Surveillance)

General approach for identifying 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 or clinical clues
  - Direct observation of eye or facial abnormalities
  - Direct ophthalmoscopy by the health care provider
  - A parent or professional's concern about the child's vision [D2]
- 2. It is recommended that risk factors for vision impairment be reviewed in all newborns (Table 7, page 42), and that children who have risk factors receive ongoing monitoring and surveillance for possible vision impairment, including vision evaluations by qualified eye specialists as needed. It is important to begin this process when a problem is suspected. [A] (Cioni 1997, Mercuri 1997, Pinto-Martin 1996)
- 3. When a young child has clinical clues of a possible vision impairment (Tables 8a, 8b, and 8c, pages 43 45), it is important to initiate appropriate assessment strategies to determine whether a vision problem exists, and to determine whether there is a need for specific interventions or surveillance. It is appropriate to begin this process when a problem is suspected. [A] (Abrahamsson 1990, Birch 1988, Cioni 1997, Darlow 1997, Johnson 1989, Mercuri 1997, Pinto-Martin 1996)
- 4. It is recommended that abnormal findings by the primary health care provider on the vision exam (Table 9, page 48) be referred for further evaluation to an eye care professional that has experience working with children. [D2]
- 5. It is important for health care providers to recognize that parental concern, even in the absence of obvious physical findings, can be an indicator of a vision problem.
  - [B] (Johnson 1989)
- 6. It is important for parents to understand that it is not always possible to identify clearly the extent of vision impairment at a young age.
  - [A] (Hope 1990, Mercuri 1999, Schmidt 1994)

## Table 9: 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 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 opacity (cloudiness) of the cornea, a cataract, or a retinal detachment or disorder.

**Binocular red reflex** (Bruckner test): 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 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 10: 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 and ability 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 (Chandna 1991). At 36 months, visual acuity is still developing (Adoh 1994, Chandna 1991).

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 six weeks of age.
- Common methods for measuring visual acuity for 2½-to-3-years old children include the use of a schematic picture or other simplified eye chart. The Tumbling Etest or HOTV matching test is often used for children three to four years of age. An adulttype Snellen chart is generally not used until children are approximately five or six years old and know their letters.
- Sometimes the visual acuity of preverbal children is estimated using more elaborate techniques such as preferential looking, (Table 12, page 62) optokinetic nystagmus, or electrophysiological methods (page 63).

## 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 (scotomata). 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 from the periphery into each of the four quadrants of the visual field. This is referred to as "confrontational" visual field testing. In older children, the examiner asks the child to communicate verbally when an object is visible.

## Table 10: General Vision Surveillance: Tests of Vision

#### 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.

(Continued from previous page)

## General health and developmental surveillance

7. General health and developmental surveillance, such as routine well-baby checkups performed routinely at specific age points, is important for all young children. It is important that general surveillance include examination of the eyes and asking questions about risk factors for and clinical clues of possible vision impairment. [D2]

Early Intervention Policy \* Monitoring and developmental surveillance for children at risk for vision problems is generally performed 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 or a diagnosed condition that has a high probability of resulting in developmental delay (Appendix D).

- 8. It is recommended that health care providers follow the guidelines established by the American Academy of Pediatrics (AAP 1996) for the scheduling of eye examinations and screening for infants and children. In particular, it is recommended that:
  - All infants be examined by six months of age to evaluate fixation preference, ocular alignment, and the presence of any eye disease
  - Infants continue to be checked yearly until three or four years of age or until such time as visual acuity and binocularity can be determined
  - Formal vision screening evaluations begin at three years of age [D2]

- 9. It is recommended that beginning in the newborn period and at each visit thereafter, the routine eye exam by the health care professional include:
  - General observation of the child's use of vision, including interaction with parent(s) and tester, and ability to maintain eye contact
  - General examination of eyelids, orbits, and pupils
  - Motility
  - Eye muscle balance
  - Red reflex [D2]
- 10. Enhanced surveillance to monitor the child's vision status, including vision evaluations as needed, is important for all children at risk for a possible vision impairment because:
  - The development of the eye, visual acuity, and the ability to use vision change as the eyes develop during the first months and early childhood, and it is not always possible to identify clearly the extent of vision impairment at a young age
  - As the child's developmental skills become more complex (from one to three years of age), a child's limitations become more apparent
  - Children who are identified with vision impairment in infancy or early childhood are at increased risk for associated developmental problems (motor, cognitive, language, etc.) [D2]
- 11. When preterm infants at risk for retinopathy of prematurity or other vision impairments are developing normally (no suspect clinical signs), specific vision intervention is generally not indicated. However, ongoing surveillance for vision problems is essential for all preterm infants.

  [B] (Darlow 1997)

### Parent report

- 12. Because parental concern can be a reliable indicator of a vision problem, it is recommended that the routine evaluation of children by the health care professional include questions about the child's visual behaviors (Table 8b, page 44). Possible questions include the following:
  - 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 assume a habitual head position?
  - Does the child tend to object to one eye being covered? [B] (Johnson 1989)

13. It is important to recognize that a child's ability to visually locate a small object (e.g., picking up a small piece of candy) is not a reliable indicator of vision ability.

[B] (Johnson 1989)

### Considerations for specific risk factors and clinical clues

Premature low birth weight infants

- 14. In very low birth weight infants (less than 1500 gms.), it is important to look for brain lesions using neuroimaging (MRI and cranial ultrasound). [A] (Cioni 1997, Pinto-Martin 1996)
- 15. It is recommended that low birth weight infants (less than 2000 gms.) with documented brain lesions (confirmed by neuroimaging in newborn period) need enhanced surveillance for vision impairments and other developmental problems through at least two years of age.

[B] (Pinto-Martin 1996)

# Retinopathy of prematurity (ROP)

- 16. 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.
  - [A] (Darlow 1997, Dobson 1999)
- 17. When preterm infants at risk for retinopathy of prematurity or other vision impairments are developing normally (no suspect clinical signs), specific vision intervention is generally not indicated. However, ongoing surveillance for vision problems is essential.

[B] (Darlow 1997)

### Periventricular leukomalacia (PVL)

18. 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. Preterm infants with PVL confirmed by neuroimaging such as MRI have a significantly increased incidence of severe vision impairment, particularly if the optic radiations and visual cortex are affected.

[B] (Cioni 1997)

19. For infants with PVL, 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 vision impairment. A child with PVL noted on MRI but with no visual cortex abnormalities is a predictor of a better outcome.

[B] (Cioni 1997)

20. When assessing children with vision impairment related to PVL, it is important to recognize that both the vision impairment and the PVL can affect motor development.

[B] (Cioni 1997)

#### Perinatal brain lesion

21. 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 vision impairment.

[B] (Pinto-Martin 1996)

- 22. In general, it is not possible to predict at the time of birth which children that have perinatal brain lesions will have vision problems. However, children at higher risk for vision problems generally include children that:
  - Have neuroimaging evidence of brain lesion and who later develop CP
  - Have a lesion in basal ganglia
     [B] (Pinto-Martin 1996, Mercuri 1997)

Absence or asymmetry of optokinetic nystagmus (OKN)

23. It is important to recognize that absence or asymmetry of OKN in any child after the age of six 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.

[B] (Cioni 1999, Mercuri 1997)

#### Screening for Amblyopia and Refractive Errors

Screening for vision impairment is intended to determine whether a child either has or does not have indications of vision impairment. The intent of screening is not to arrive at a formal diagnosis, but rather to identify children with an increased likelihood of vision impairment, and who therefore need further assessment to determine if the condition exists and to establish the diagnosis. 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 (Table 9, page 48).

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. 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) Preslan 1993, Tong 20000

### Screening for amblyopia

Functional amblyopia is an unexplained reduction in clearness of vision (subnormal visual acuity) 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 who have strabismus often develop amblyopia in the affected eye.

With functional amblyopia, there is no visible organic lesion or pathological basis for the vision loss (D'Alonzo 1991, Menacker 1993). Amblyopia occurs 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 (Menacker 1993, von Noorden 1990). 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 (Menacker 1993). Although visual maturation is generally thought to occur by approximately seven years of age, there may still be some plasticity of the visual system well beyond childhood.

Using photo-technology to screen for amblyopia and refractive errors

Recently, the use of photo-technology has been used to screen for amblyopia. Photoscreeners (sometimes called photorefractors) are special cameras that take a picture of the eye at a single point in time. Using flash photography, photoscreeners provide a picture of the red reflex, the light reflections that occur when light is refracted on entry and exit from the eye. A grader examines the photograph looking for information about possible amblyogenic factors. The way the red reflex is displayed in the photograph gives information about the refractive errors (nearsightedness or farsightedness). Depending on the technique used, information can be obtained from the photograph about difference in eye focus, alignment, eye turn, and cataracts.

Because the photography procedure is noninvasive, it requires the child to focus only briefly for the photograph and can be performed by technicians. Photoscreeners have been considered as 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. However, technicians can easily use the machine because the computer chip automatically adjusts the focus. This type of device is not generally considered a screening device, but rather a tool involved in the assessment by an eye care professional.

# Recommendations (Screening for Amblyopia and Refractive Errors)

Early Intervention Policy 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 Early Intervention Program services. However, it is important to identify and appropriately treat children who have correctable vision problems to prevent future deterioration of vision.

Important considerations for screening programs

- 1. 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 [D2]
- 2. When conducting a vision screening program for young children, important goals include:
  - To identify children with the condition or with risk factors for the condition where a timely diagnosis would affect the outcome (a delay in initiating intervention would make a difference)
  - To identify children who may have the condition and differentiate them from those with a low likelihood of having the condition [D2]
- When designing a screening program to detect vision problems in young children, it is important to:
  - Define the target conditions to be identified
  - Define the population and the expected prevalence of the condition in that population
  - Use a test that has a reasonable sensitivity/specificity for correctly identifying the target condition for the selected population
  - Establish mechanisms to follow up abnormal screening results
  - Know what to tell the parent about the results of the screen (if the child fails the screen/if the child passes the screen) [D2]
- 4. When evaluating the effectiveness of a screening test, it is important to use a reference standard that measures the same thing and to remember that the sensitivity/specificity of a test will vary depending on the cutoff. [D2]

### Use of photoscreeners/photorefractors/autorefractors

5. It is important to recognize that photorefractors are generally more difficult to use and have limited usefulness in children younger than 36 months because the process requires that the child be able to maintain a stationary position and fixate on the object while the picture is taken.

[A] (Atkinson 1984, Hamer 1992, Hodi 1994, Hope 1994, Preslan 1993, Williams 2000)

- 6. It is recommended that photoscreeners not be used for widespread screening of young children (from birth to three years of age). The technology and the materials (film) are relatively expensive, and the results have not demonstrated that this approach adequately and reliably identifies young children who need further evaluation for possible vision problems.
  - [A] (Cooper 1999, Cordonnier 1999, Hamer 1992, Simons 1999, Tong 2000)
- 7. It is important to recognize that autorefractors, while not useful for overall screening for refractive errors in young children (from birth to three years of age), may be helpful when detecting astigmatism (one type of refractive error).
  - [B] (Cordonnier 1999)
- 8. It is important to remember that a test is valid only to the extent of the training and experience of the person administering the test or interpreting the test results. It is also important to recognize that when using a photoscreener, there can be significant differences between raters, even well-trained professionals, when interpreting the results.
  - [A] (Hope 1994, Simons 1999, Tong 1998)

### **ASSESSMENT OF VISUAL STATUS**

**Evidence Ratings:** 

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[A] = Strong [B] = Moderate [C] = Limited
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[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

This section evaluates some specific techniques for assessment of visual status. Assessment of other aspects of the child's development and assessment of health concerns, both of which are important aspects of assessing children with vision impairment, are discussed in other sections of this chapter.

Topics covered in this section:

- Ophthalmic Examination
- Electrophysiologic Assessment Methods
- Assessment of Visual Function

Basis for the recommendations in this section

The evidence-based recommendations in this section are derived from the studies that met the criteria for evidence for this topic. Some parts of this section

also include consensus recommendations that generally relate to approaches for which the literature was not specifically reviewed, or for which no scientific evidence was found that met the criteria for this guideline. Some of the recommendations are based on information from review articles that were considered by the panel in the absence of specific studies meeting the criteria for evidence. In the panel's opinion, these recommendations reflect appropriate practices for assessing children with vision impairment, and are generally consistent with the current knowledge in this field.

### **Ophthalmic Examination**

An ophthalmic evaluation provides a more in-depth assessment of the visual status of children who either have or are suspected of having vision impairment. The ophthalmic examination is intended to further evaluate children when vision impairment is possible due to risk factors and clinical clues, parental or professionals' concerns, and/or positive screening test results. Ophthalmic evaluation can be used in several ways to assess children with possible vision impairment, including to:

- Determine whether vision impairment is present
- Establish a specific diagnosis and assess the severity and specific attributes of the vision impairment
- Determine whether intervention is indicated and help 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 11: Components of the Basic Ophthalmic Exam

The basic eye exam performed by eye care professionals includes all the components of a general vision surveillance eye exam (Tables 9 and 10, pages 48-49) in addition to the following:

#### 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, in particular the media and the fundus, or the posterior inner part of the eye.

### **Biomicroscopy** (slit lamp examination)

Biomicroscopy provides a highly magnified view of the various structures of the eye. The angle of the anterior chamber and regions of the fundus can also be examined with the slit lamp. 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 eye drops accomplish two things:

- Mydriasis (dilation of the pupil)
- Cycloplegia (paralysis of the muscle that controls the lens of the eye to prevent the eye from focusing)

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

- Nearsightedness (myopia)--the light rays come into focus in front of the retina.
   Objects in the distance are blurred.
- Farsightedness (hyperopia)--the light rays encounter the retina before they are in focus. In general, this is a normal condition in young children, and most young children are able to compensate for normal levels of hyperopia.
- Astigmatism--blurring or distortion of vision at all distances due to the nonspherical (not round) curvature of the cornea or lens. Astigmatism may be present by itself or combined with myopia or hyperopia.

For significant refractive errors, glasses may need to be prescribed.

#### **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 is to detect glaucoma, a disease characterized by increased intraocular pressure.

# **Table 12: Vision Assessment Approaches**

### **Preferential Looking Techniques**

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.

## **Recommendations (Ophthalmic Examination)**

Preferential looking techniques

- Preferential looking is a valid test to measure visual acuity (monocular and binocular grating acuity) and detect vision deficits in preverbal children. [B] (Birch 1988)
- When assessing vision in a preverbal child using preferential looking techniques, it is important to familiarize the child with the test and then ascertain that the child is responding appropriately before assessing the child's acuity.

[B] (Birch 1988)

## Teller Acuity Cards (TAC)

- 3. It is important to understand that as a gross assessment of visual status, Teller Acuity Cards can provide a relatively accurate assessment of visual acuity in preverbal children as young as four months of age. However, for children who have developed language, measurements of acuity using letter charts can be more accurate than acuity measurements using TAC.

  [A] (Hall 2000, Mash 1998)
- 4. When using Teller Acuity Cards, it is important to understand that the scores provide information about how the child is doing at the time of the test. The results in young children are not always a reliable indicator of future acuity. Therefore, it is recommended that children whose TAC test results indicate low visual acuity and who have no other abnormal finding on the ophthalmic exam receive enhanced vision surveillance and periodic vision testing.

  [A] (Dobson 1999, Hall 2000, Mash 1998, Spierer 1999)
- 5. It is important to recognize that while they may adequately identify young children with vision impairment, Teller Acuity Cards miss many children who have a problem. In other words, TAC tend to be better at identifying children with normal vision than identifying children with abnormal vision. [A] (Dobson 1999, Hall 2000, Marsh-Tootle 1994)
- 6. It is important to recognize that if a child has a neurodevelopmental delay and tests normal with Teller Acuity Cards at the age of one year, this result is not always a reliable indicator of how the child will test later. Reliability increases when the child is older.

[A] (Dobson 1999, Hall 2000, Mash 1998, Spierer 1999)

- 7. When a child is not able to respond to other tests, modified Teller Acuity Cards using pointing may be useful for identifying amblyopia and obtaining a gross estimate of visual acuity. [D2]
- 8. Using Teller Acuity Cards requires the following optimal testing conditions:
  - Adequate lighting
  - Nondistracting testing environment
  - Clean cards that are in good condition
  - An alert and attentive child [D2]

## Recording and interpreting Teller Acuity Card (TAC) results

- 9. It is important to recognize the factors inherent in the test structure of TAC that can influence accuracy of measurement. For example, interrater reliability may be an issue because interpreting TAC results is more subjective than some other tests because they require interpretation of the child's behavior.
  - [A] (Dobson 1999, Hall 2000, Mash 1998, Spierer 1999)
- 10. When interpreting TAC results, it is important to remember that other impairments, such as motor or cognitive impairment, may influence the child's performance. [D2]
- 11. It is important to recognize that TAC results are recorded in cycles per degree second (CPD). Although TAC results are often translated into equivalent Snellen values, it is important to understand that TAC results do not directly correlate to Snellen equivalents. [D2]

#### Random Dot E test

- 12. Children who have a normal response to the Random Dot E test have a high likelihood of having good vision in several categories:
  - Good visual acuity
  - Equally good vision in both eyes (no amblyopia)
  - Good alignment (no strabismus)
  - Good binocularity (ability to use both eyes at the same time) [A] (Hope 1990, Schmidt 1994)
- 13. The Random Dot E test can be used as an indicator of binocular vision status in preverbal children as young as six months. It is important to understand that this test is a relatively good predictor when the results are normal. In preverbal children, this test can be administered using preferential looking techniques.

[A] (Hope 1990, Schmidt 1994)

14. The Random Dot E test may be useful as a test of binocularity, but it is recommended that it not be used as the sole test. It is important to recognize that some children who have poor vision will be able to pass this test. [A] (Hope 1990, Schmidt 1994)

### **Electrophysiologic 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. In the last twenty years, there have been significant advances in neuroimaging. Even relatively small lesions (or what were previously considered inconsequential) can now be correlated with clinical conditions.

There are several ways to image the central nervous system:

- Conventional x-ray of the skull visualizes severely small or large heads (microcrania or macrocrania), which can often be clinically detected as well. Calcifications inside the head (intracranial) can be seen but are better visualized on Computerized Axial Tomography (CT) scan. X-rays are 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 (e.g., brain lesions). For ultrasound, one needs an acoustic window. A fontanel is perfect, but it often closes after a few months. Therefore, ultrasound is the most useful in the newborn period. It is inexpensive and portable (it can be brought to the bedside), and it provides an instant assessment.
- Computerized Axial Tomography (CT or CAT) scanning is performed by a narrow rotating x-ray beam that hits crystal detectors located in a circle around the perimeter of the CT scanner. It allows one to see spinal fluid-filled cavities and bone particularly well. However, what are often not seen are changes in the posterior fossa (back part of the brain) and changes in consistencies of areas of the brain such as leukomalacia or softening of the white matter. The technology for CT scanning has become so proficient that an entire brain CT scan can be performed in a few minutes. The patient needs to be 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. MRI involves a large magnet with a large magnetic field that creates the reconstructed images on the screen. All areas of the brain and all lesions (vascular, spinal fluid, oncologic, etc.) are visualized well. The patient is required to stay motionless for a prolonged period. 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 stimulation of 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.

## **Recommendations (Electrophysiologic Assessment Methods)**

Visual evoked potential (VEP)

- 1. 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 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 [C] (Clarke 1997, Mercuri 1999)

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 are
apparently blind who seem to have a normal eye exam by an eye care
professional.

[C] (Clarke 1997, Mercuri 1999)

# **Visual Function Assessment**

A visual function assessment is not an assessment of a child's eyes or visual status, but rather how the child uses vision to interact with the environment. The purpose of a visual function assessment is to examine the extent to which and the way in which the child uses any residual vision that exists. Areas addressed in a visual function assessment generally include optical and optical/perceptual discrimination, recognition and identification visual memory, spatial perception, and visual-motor coordination (Davidson 1986).

Methods for assessing visual function include the use of specific assessment instruments and observation of the child performing everyday/routine tasks. Examples of published checklists and protocols that may be used to assess visual function include:

- Vision Assessment and Curriculum Reference (Utah School for the Blind)
- Peabody Model Vision Project: Functional Vision Inventory
- Look at Me: A Resource Manual for the Development of Residual Vision in Multiply Impaired Children
- Individualized Systematic Assessment of Visual Efficiency (ISAVE)
   (American Printing House for the Blind)

Information from the visual function assessment can provide a mechanism for the evaluator to communicate observations about the child's vision to the child's physician, eye care professional, other professionals, and parents.

## Table 13: General Components of a Visual Function Assessment

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

- 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

### **Table 13: General Components of a Visual Function Assessment**

- 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, and color
- Visual motor (e.g., midline hand play, object manipulation, and bead stringing)
- Eye preference
- Figure-ground discrimination
- Convergence and eye teaming skills (the ability of the eyes to aim, move, and work as a coordinated team)

(Continued from previous page)



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.

## **Recommendations (Assessment of Visual Function)**

- 1. It is important to conduct the visual function component of a child's assessment before assessing other developmental domains, such as cognition and sensorimotor development. This will allow the evaluator 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. [D2]
- It is important to consider the child's cognitive, communication, and sensorimotor development level when assessing visual function because the ability to use vision is related to cognitive development. 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 planning intervention strategies. [D2]
- 3. It is important to monitor and periodically reassess visual function in young children with vision impairment. [D2]

## **DEVELOPMENTAL ASSESSMENT**

Evidence Ratings:[A] = Strong [B] = Moderate [C] = Limited [dc] = Developmental characteristics study [D1] = No evidence meeting criteria [D2] = Literature not reviewed

This section covers the basic aspects of the developmental assessment for young children with vision impairment. Topics include:

- General Approach to Developmental Assessment
- Assessment of Cognition
- Assessment of Sensory and Motor Development
- Assessment of Communication
- Assessment of Adaptive/Self-Help Skills
- Assessment of Social/Emotional Development

Basis for the recommendations in this section

Some of the recommendations for assessment of developmental domains for young children with vision impairment are based on information from articles meeting the criteria for evidence about the developmental characteristics of young children with vision impairment. Other recommendations are panel consensus opinion. The articles meeting the criteria for evidence are primarily articles describing some of the specific developmental characteristics of young children with vision impairment. The guideline panel made consensus recommendations when scientific literature was not found for a topic or when the scientific literature was not specifically reviewed as a focus of this guideline. In the panel's opinion, these recommendations reflect appropriate practices for assessing children with vision impairment and are generally consistent with the scientific knowledge in this field.

## **General Approach to Developmental Assessment**

Many young children identified as having vision impairment will also have other developmental problems. While correcting a child's vision to the extent possible is usually the first consideration related to vision impairment, the impact of vision impairment on the child's development is also critically important.

Vision impairment can affect all areas of development. Acquisition of developmental skills in young children with vision impairment is often delayed and often differs in sequence from typically developing children. For children with vision impairment, a major source of sensory information is either reduced

or not available, which may result in a tendency to withdraw from interacting with the immediate environment. Interaction with the environment is an important component of how young children learn and grow developmentally.

Children with vision impairment present with a wide range of visual abilities and developmental profiles. Children who have similar visual abilities will not necessarily have similar 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.

### The developmental assessment

A developmental assessment for children under three years of age is an attempt to assess the child's functioning in a variety of environments. 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. The home and the other environments that are commonly part of the life of the child and family are important components understanding the developmental profile of the child.

## **Recommendations (General Approach to Developmental Assessment)**

Importance of the developmental assessment

 It is recommended that all young children with vision impairment have ongoing, age-appropriate developmental monitoring and assessment. This is important because vision plays an important role in developmental growth, and young children with vision impairment often have developmental delays.

[Cdc] (Hatton 1997, Levitzion-Korach 2000, Parsons 1986, Troester 1996)

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 development). The multidisciplinary evaluation is provided at no cost to parents.

- 2. Developmental assessments are important for children with vision impairment because developmental assessments 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 [D2]
- 3. When assessing development in young children with vision impairment, it is important for those assessing the child to understand the whole child and to consider any factors (in addition to the child's visual status, such as health status, hearing status, and family or environmental factors) that may have an impact on the child's performance. [D2]

Importance of assessing vision in children who have developmental delays

4. When it is determined that a child has a developmental delay, it is important to consider the need for an eye examination in order to rule out a related vision impairment. [D2]

# The developmental assessment process

- 5. It is important that the developmental assessment be viewed as not just a single event. After the initial assessment, it is important to continue monitoring the child's development, including periodic reassessment of the child's progress over time. [D2]
- 6. Developmental assessments can be performed by a variety of professionals in a number of settings. Depending on the needs of the child, it may be important for the assessment process to include observation or assessment of the child at more than one session and in more than one setting (e.g., the home, child care setting, school, and typical social environments), as appropriate, because:
  - A child's performance can vary from day to day and setting to setting
  - Multiple sessions may be needed to sustain the child's attention
  - A child's comfort level with the professional may change over time [D2]
- 7. It is important that the developmental assessment of young children with vision impairment include multiple testing modalities, (such as pictures, objects, sounds, textures, vibration, and movement), assessment approaches (such as assessment instruments, observation, and parent report), and examiners. [D1]
- 8. It is important that the developmental assessment:
  - Be individualized for each child and family
  - Use age-appropriate testing and scoring methods
  - Utilize procedures that are reproducible by other professionals

- Assess the child's presenting problems
- Define the child's strengths and/or compensatory abilities
- Consider the child's individual abilities and needs, including specific discrepancies in functioning across and within developmental domains
- Make use of parents' observations of their child's skills and behaviors
   [D1]
- 9. 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. [D2]

# Including the parents in the assessment process

- 10. It is recommended that a parent or other primary caregiver be present for the formal assessment whenever possible and that there be an opportunity for other family members to participate in the process. [D2]
- 11. It is important to include information from a parent report of the child's performance in the child's natural setting. [D2]

### Assessment strategies, materials, and settings

- 12. It is recommended that the assessment strategies, materials, and the setting in which the assessment is performed be developmentally appropriate for a young child who has vision impairment and that the setting be comfortable for both parent and child. [D2]
- 13. It is recommended that the developmental assessment of young children with vision impairment include assessment in the child's home or other natural environments when possible. [D2]
- 14. 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. [D2]
- 15. When selecting assessment materials and procedures, it is recommended that the child's sensory capacities and modes of responding be considered to the extent that:
  - If a young child has significant visual or motor limitations, then
    adaptations of materials, setting, or testing/response procedures may be
    necessary if the assessment results are to reflect accurately the child's
    development

• The input of parents and others who know the child well can be particularly important in determining the most appropriate materials, procedures, and adaptations to be used [D1]



Early Intervention Policy • The multidisciplinary evaluation team can use a combination of standardized instruments and procedures, and informed clinical opinion to determine a child's eligibility for services.

The multidisciplinary evaluation should include a parent interview. The interview may be a formal interview or an informal discussion with the parent.

### General developmental assessment tests

- 16. It is important to understand that not all general developmental assessments are designed or adapted for use with young children with vision impairment. [D1]
- 17. When using developmental assessment tests (Table 14, page 72) that are not normed for children with vision impairment, it is important to recognize that they may have limited applicability to this population, and interpretation should be made with caution. [D1]
- 18. It may be useful to use both general tests of development not specific to vision impairment (e.g., HELP) and tests developed specifically for children with vision impairment (e.g., Oregon). Comparing the results from both types of tests provides a more detailed description of the child's abilities. [D2]

# **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, such as 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 14: 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 mos 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 or 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 perception, language, play, and daily living skills	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.		
Functional Scheme: Functional Skills Assessment	Fine and gross motor, perceptual, spatial and object perception, and social/emotional	Birth- 48 mos.		

<b>Table 14:</b>	General Developmental Assess	ment Tests
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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 C for additional information about Developmental Assessment Tests.)			

(Continued from previous page)

### Components of the developmental assessment

- 19. There are two important components for assessing the development of children with vision impairment: 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). [D2]
- 20. It is important that the developmental assessment to include both qualitative (descriptive information) and quantitative (test scores) measures. [D2]
- 21. 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
  - 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 [D2]

- 22. It is important that the developmental assessment include:
  - Observational data obtained in the child's natural environment, including observation of the child during informal and structured play, and parent-child interactions
  - Parent reports and interviews to elicit concerns, obtain a history of the child's early development, and gather information about the child's current level of functioning [D2]
- 23. In children with vision impairment, it is important to assess the need for assistive technology (page 96) to support the child's:
  - Interaction with and use of materials
  - Communication
  - Mobility/positioning [D2]

### Assessing developmental milestones

- 24. When assessing any young child, it is important to assess developmental milestone progress. This is important because it gives parents, professionals, and others caring for the child:
  - A better understanding of the developmental status of an individual child
  - Help when making appropriate decisions about the focus, timing, and sequence for interventions [D2]
- 25. When assessing children with vision impairment, it is important to recognize that the point at which children attain specific developmental milestones will vary.
  - [Bdc] (Hatton 1997, Levitzion-Korach 2000, Parsons 1985, Troester 1994, Troester 1996)
- 26. It is important to remember when assessing developmental milestones in children with vision impairment that most developmental assessment tests have not been standardized for children with vision impairment and are usually dependent on vision, and therefore may not accurately reflect (may underestimate) the true developmental status of the child. [D2]

### Important adaptations for children with vision impairment

- 27. In assessing general development in children with vision impairment, it is helpful to use qualitative assessment using examiner's observation of the child exploring the environment and reaction to stimuli. Doing this effectively involves structuring the testing environment to promote active exploration by the child. This might include:
  - Presenting objects so they touch the body
  - Adjusting the lighting for the comfort of the child
  - Presenting objects in different areas of the 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, taste and smell, size, and colored lights that are of high interest to the child
  - Positioning the child with appropriate support to facilitate motor activity
  - Using high contrast materials for children who have low vision [D2]

## Interpreting assessment results

- 28. When interpreting the results of developmental assessment testing, it is important to recognize that children with vision impairment may have qualitative developmental differences (different patterns of development that are common to children with vision impairment) when compared to typically developing children or other children with developmental delays. [Bdc] (Levitzion-Korach 2000, Parsons 1985, Parson 1986, Troester 1994)
- 29. It is important that the results differentiate between the score on the test and the child's actual performance. This is important because in some cases a standard score on the test may not reflect the true ability of the child. [D2]
- 30. When interpreting the assessment results, it is important to look at how the child completes each task, the quality of the performance, and the method used. [D2]
- 31. It is important to note the points at which the child is not able to complete tasks that are part of the assessment. It is not enough to know only what the child is able to see and do. It is important to know also what the child is not able to do in order to develop a baseline and design an appropriate intervention program. [D2]

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.

Communicating findings to parents and other professionals

- 32. It is recommended that an explanation of the results of the assessment be provided in a timely manner to the family. The result should be translated into the child and family's dominant language when possible. It is useful to discuss:
  - · Important terms and concepts used
  - The results and implications of the assessment
  - Performance in relation to expected developmental milestones and how developmental milestones might be affected by vision [D2]
- 33. It is important for all professionals involved in the assessment of a child with vision impairment to communicate with each other regarding their findings and recommendations to ensure a comprehensive assessment. [D2]
- 34. It is recommended that reports from professionals that assess children with vision impairment contain:
  - Results presented in language that is understandable to the family and other professionals working with the child
  - Strengths and limitations of the assessment tools or processes
  - Information about how the child's developmental level may affect the child's functional skills in activities of daily living
  - Results that are useful for developing intervention goals [D2]

Early Intervention Policy & Under the Early Intervention Program, the evaluator is responsible for sharing the results of the evaluation with the child's family and ensuring the family understands the results and implications of the evaluation for intervention.

Using the findings of the developmental assessment

35. It is important that the findings of the developmental assessment be used to develop any intervention programs 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. [D2]

## **Assessment of Cognition**

Cognitive development depends on a child's cumulative and interrelated sensory experiences. The sensory input from vision, hearing, and tactile exploration are significant components of a child's early sensory experiences. Typically, the ability to localize and explore visually develops before the ability to localize sound and to explore tactilely. Therefore, children with vision impairment do not have the same early access to sensory experiences as do children who are not visually impaired. Without the full use of vision to connect the various sensory inputs, 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 some cognitive skills may begin later in some children with vision impairment (Trzasko 1992).

In general, when compared to 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 because of 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) (Ferrell 1985, Lueck 1997)
- Orientation (understanding where they 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 combine the above skills to create specific changes in the environment)

Some of these differences in the way that children with vision impairment experience their environment may explain why these children tend to differ from sighted children in the acquisition of cognitive, motor, and other developmental skills.

# Measuring cognition

There are norm-referenced and criterion-referenced developmental assessments that assess cognitive ability. However, there are no tests to measure cognition that are designed specifically for children with vision impairment that will result in a standard score or a standard deviation score (Trzasko 1992).

## **Recommendations (Assessment of Cognition)**

Importance of assessing cognition in children with vision impairment

- 1. It is important to assess cognitive ability in children with vision impairment because the child's cognitive ability:
  - Affects all other areas of development
  - Helps determine the kinds of interventions that are most appropriate
  - Provides a baseline for measuring progress [D2]

Conducting the cognitive assessment

- 2. 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 tactilely explore the object
  - Use items that have high contrast if the child has some vision
  - 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 when vision is not a viable input channel [D2]

## Components of the cognitive assessment

- 3. 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:
  - Curriculum-linked, standardized, norm-referenced, or criterion-referenced assessments as available and appropriate (Table 14, page 72)
  - Observational tools and procedures
  - Parent interview
  - Routine-based assessment (i.e., the parent and professional working together to analyze the child's daily routines in order to identify appropriate activities for teaching or encouraging essential skills [D2]
- 4. When assessing a child's cognitive level, it is useful to:
  - Observe the child during structured and free play
  - Observe the child's interactions with people and objects in varied environments
  - Include opportunities for the child to manipulate various objects and to orally explore and listen to different stimuli
  - Evaluate social exploratory behavior
  - Allow for testing to be conducted over several sessions if needed
  - Consider environmental influences, such as parent teaching style [D2]
- 5. It is important to remember that when a child is young, performance on cognitive tests may fluctuate based on a variety of factors. The scores of cognitive tests of young children are often not stable and are not necessarily predictive of future ability. Therefore, cognition may not be adequately measured in a single session or single setting. [D2]

Cognitive assessment tests for children with vision impairment

- 6. Developmental assessments (Table 14, page 72) 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. [D2]
- 7. When considering developmental test options to measure cognition in young children with vision impairment, it is important to recognize that:
  - There are no norm-referenced tests to assess cognition that are designed specifically for children with vision impairment (except for the Reynell-Zinkin, which is out of print)
  - Most criterion-referenced tests designed specifically for children with vision impairment contain a cognitive development section
  - The Bayley and the Mullen are standardized tests that measure cognition, but they do not include specific adaptations for children with vision impairment
  - The Battelle contains adaptations for administering test items to children with vision impairment, but the scores were not standardized for these children [D2]

# **Assessment of Sensory and Motor Development**

Because vision plays a significant role in the developmental process, delays can occur in all areas of development. Motor development is usually the most observable aspect of a young child's early development, and therefore delays in motor development are often one of the early indicators of other problems, such as vision impairment. Children with significant vision 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, the delay in motor development may be more apparent later, such as when the child's crawling or walking is delayed.

The majority of sensory and motor development occurs during the first year of life. Development of righting reactions and then rotation and postural tone will be delayed if a baby who is severely visually impaired is not provided the vestibular, proprioceptive, and tactile sensory stimulation. Because of reduced visual sensory input and related low postural tone, the child who is visually impaired 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 in all positions (SKI-HI Institute 1995, Leong 1996). Without appropriate intervention, children with vision impairment tend to maintain immature patterns of gait because of low postural tone and incomplete sensory-motor development (SKI-HI Institute 1995, Leong 1996).

Children with vision impairment tend to be slower in progressing through their developmental motor milestones and demonstrate characteristic variations in this development (Table 16, page 84). However, babies with vision impairment generally have the same potential to learn movement as sighted babies do. With proper identification, assessment, and intervention during the critical stages of sensory-motor development, most children can learn to compensate for their loss of vision (SKI-HI Institute 1995).

# **Recommendations (Assessment of Sensory and Motor Development)**

*Understanding the relationship between vision and motor development:* 

- When assessing sensory and motor development in infants and young children, it is important to:
  - Determine whether delays in motor development are due to vision impairment (lack of visual information resulting in decreased motivation to explore and develop motor skills) or to a neurologic or orthopedic condition
  - Take into consideration the role that vision plays in the development of postural control, goal-directed movement, and establishing balance
  - 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 [D2]
- It is important to understand how visual information provides sensory stimulation to motivate movement as well as feedback that facilitates continuous correction of movement. Visual information provides the basis for activities such as reach and grasp, postural adjustment and control, and locomotion. [D2]
- 3. When assessing the motor development of a child who has vision impairment, it is important to consider the severity of the vision impairment and to assess the child's development relative to children who have comparable vision impairments as well as to typically developing children. [D2]

Components of the assessment of motor development

- 4. It is important to consider the following when assessing motor development and functioning in young children with vision impairment:
  - The interrelationship between the child's cognitive development and motor development
  - The child's receptive language skills
  - The child's overall health status and neurologic function [D2]
- 5. The use of criterion-referenced or norm-referenced developmental motor assessment tests may be useful when assessing motor function in young children with vision impairment. However, it is important to recognize that not all of these have been standardized for young children with vision impairment. [D2]

## **Table 15: 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 (Table 16, page 84)

## Specific assessment approaches

6. 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 give a false impression that the motor development is progressing normally in young infants with vision impairment. It is important to include assessment of:

- Compensatory movement strategies that may be interfering 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 [D2]
- 7. It is important to provide appropriate postural support when assessing young children with vision impairment and to make appropriate accommodations for any motor limitations. For example, consider:
  - Appropriate positioning/supportive seating
  - Appropriate seat height, depth, and width with feet touching the floor or on a raised platform
  - Appropriate table height, depth, and width
  - Direct support/facilitation of the child as tolerated
  - Use of prescribed orthotics such as braces or hand splints [D2]
- 8. In 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 detract from or enhance motor activity). [D2]
- 9. It is important to consider the child's developmental progress relative to both children with vision impairment and typically developing children. When assessing developmental milestones (Table 16, page 84), it is important to recognize that the point at which children attain specific developmental milestones will vary.
  - [Bdc] (Hatton 1997, Levitzion-Korach 2000, Parsons 1985, Troester 1994, Troester 1996)

	Age Range (in months)		Median Age (in months)	
Milestone	Sighted	Blind	Sighted	Blind
Elevates self by arms when 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
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

10. It is important that the assessment of motor function not be limited to an evaluation of the child's progress in attaining motor milestones. When assessing motor development in young children with vision impairment, it is important also to obtain an adequate assessment of the quality of movements. [D2]

# Assessment of sensory processing

- 11. Since children with vision impairment will be using senses other than vision to gather information from the environment, it is important to assess the child's responses to sensory stimulation. This is usually accomplished through parent interviews and questionnaires, such as the Infant/Toddler Sensory Profile. It is important to be aware of the impact of environmental stimuli on the child's performance. [D2]
- 12. When assessing sensory responses in young children with vision impairment, it is important to focus on the child's typical response to environmental stimuli such as noise, movement, touch, smells, and tastes. [D2]

13. It is recommended that assessment of sensory processing include questions to determine whether there are concerns regarding sleep patterns, irritability, and responses to changes in schedule.

[Cdc] (Mindell 1997, Troester 1996)

#### **Assessment of Communication**

Communication is the process by which individuals exchange information and convey ideas. Communication involves much more than just speaking. At an early age, children attempt to elicit interaction with their parents. When held, a baby can make sounds, snuggle, tense, or relax to let the parent know what is needed. Soon the child is looking toward the caregiver and vocalizing for attention or smiling 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 vision impairment, children have ways of communicating with their parents. The parents need to learn the child's subtle cues, such as quieting in response to sound. Using touch in combination with talking is generally an effective component of communicating with the child. Sensory input that the child can understand, such as touch and talking, can help the child focus on the interaction.

Children with vision impairment but no other developmental delays may 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 (SKI-HI Institute, 1995). However, other areas of communication development usually differ. For example, young children with vision impairment:

- Need more verbal information and descriptions for objects and events
- May not easily attach verbal labels to tactile 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 (SKI-HI Institute 1995)

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

#### **Recommendations (Assessment of Communication)**

Communication development in young children with vision impairment

- It is important to remember that there are many aspects to communication. Communication is more than just speaking and listening. Communication includes gestures and facial expressions. 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. [D2]
- 2. It is important to remember 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 may include:
  - Less frequent or less noticeable smiles
  - Nonrecognition of the parent's voice until the infant is touched and handled by the parent
  - Requiring more time and more repetition of activities before responding
  - Requiring touch cues to sustain interactions [D2]
- 3. It is important to understand that for children with vision impairment, there may be a lag in the production of words, and vocabulary may develop more slowly than it does in sighted children 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 [D2]

# Conducting the assessment

4. Communication is a complex area involving social intent, listening skills, gestures, sound production, construction of sentences, and types of sentences. Communication evaluation should be conducted by those with training and experience in the assessment and treatment of all aspects of communication. [D2]

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

# Recommendations (Assessment of Adaptive/Self-Help Skills)

# Conducting the assessment

1. When assessing adaptive/self-help skills, it is important to recognize that there are general as well as individual developmental 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. [D2]

- 2. It is important 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. [D2]
- 3. It is important that the setting for the assessment of adaptive/self-help skills:
  - Have minimal distractions
  - Include a variety of test items
  - Take place in areas that the child associates with those activities
  - Have variable or a variety of lighting
  - Use both familiar and unfamiliar items of different sizes and levels of difficulty [D2]
- 4. It is important for the professional conducting the assessment to:
  - Be sensitive to the comfort level of the child and the parents, especially around issues of bodily contact and hygiene
  - Be familiar with patterns of development that are typical for children with vision impairment
  - Consider the child's environment and the natural opportunities for the child to develop/use independent self-care skills [D2]
- 5. It is important for the professional conducting the assessment to obtain information about:
  - The child's eye condition and severity of vision loss
  - Amount of residual vision
  - Any health/developmental/background information that might have an impact on the child's development
  - How the child uses vision in functional settings including the home, familiar areas outside the home, and unfamiliar areas [D2]
- Important strategies for 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 [D2]

7. It is important to understand the cognitive level, developmental age, and motor abilities (gross and fine motor) when assessing adaptive/self-help skills. [D2]

Components of the adaptive/self-help assessment

- 8. Important components of assessing adaptive/self-help skills include:
  - Eating/drinking (what kinds of foods/liquids, what kind of utensils and in what position, 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, washing/drying 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) [D2]

#### Assessment of Social/Emotional Development

The social/emotional domain refers to the abilities to form attachments, develop a sense of an individual self, express feelings, learn rules or expectations, and interact socially with peers and adults (Parks 1992). It involves the ability to participate in early reciprocal interactions with parents and later, in the second year of life, with peers (Lueck 1997). 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 (Ferrell 1985), initiating and maintaining social interactions (Erwin 1994), imitation, and turntaking.

Social interactions with young children with vision impairment may be more difficult to elicit and interpret than interactions with typically developing children. Children with vision impairment tend to have a more limited repertoire of facial expressions and be less responsive than sighted children. In addition, the lack of visual perception appears to delay the acquisition of a dialogue concept (Troster 1992).

"The ability to process visual information plays an important role in the social-communicative process. Not only do the eyes relay messages, but they also serve as a primary tool for retrieving information during social encounters" (Erwin 1994). Compared to typically developing children, young children with vision impairment tend to take less initiative in social interactions.

The degree to which a child's social skills may be limited by lack of sight depends in part on the severity of the vision impairment. Some children with vision impairment will have enough vision to imitate others and to observe the facial expressions of others.

# **Recommendations (Assessment of Social/Emotional Development)**

Importance of assessing social interactions and relationships

- It is important to assess social interactions and relationships in children with vision impairment because of the potential impact on intervention decisions.
   [D2]
- 2. It is important to consider 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 a restricted repertoire of facial expressions
  - Gaze, smile, or have decreased or absent eye contact when typically 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)
  - Demonstrate separation anxiety at a later age than do sighted children (object permanence develops later in children with vision impairment)
  - Demonstrate avoidance reactions to strangers only when the stranger touches or attempts to pick up the child, not in response to a stranger's voice
  - Are less responsive to games that involve objects (ball play) than sighted peers are
  - Fail to initiate social interactions [Cdc] (Hatton 1997)

# Conducting the assessment

- 3. When assessing social development, it is important to consider the child's:
  - Cognitive skills
  - Receptive and expressive language skills
  - General health, including hearing status
  - Degree of visual impairment
  - Use of functional vision
  - Gross and fine motor skills [D2]
- 4. Time, place, and other child-specific factors (health, hunger, time of day, familiarity and comfort with the evaluator) are important when planning for assessments and considering the results of the assessment. To the extent that it is reasonable, it is recommended that the child be assessed in multiple sessions and in a variety of environments relevant to the child's daily life. [D2]
- 5. As with all other areas of development, the child's environment, especially the home and family environment, can play a significant role in the child's social development. When assessing social development, it is important to consider:
  - The cultural values and social rules or customs of the family that may influence social development or the acquisition of social skills
  - The child's home and other environments with regard to opportunities for nurturing, stimulation, and learning, or lack thereof
  - Any significant family history factors that may affect the child's development of social skills
  - The impact of the family's (immediate and extended) emotional response to having a child who is visually impaired [D2]
- 6. When assessing the social development of young children with vision impairment, it is important to include direct observation of the child's interactions with others (parents, caregivers, siblings, other children, service providers), as well as information from the child's parents. [D2]

# Components of the social interactions assessment

- Important components of assessing social interactions and relationships include assessment of:
  - Sense of autonomy
  - Social initiation and 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/activity) [D2]

# Specific assessment approaches

- 8. It is recommended that a norm-referenced test (e.g., the Maxfield-Bucholz Social Maturity Scale for Blind Preschool Children) be considered as a component of the assessment of social development of young children with vision impairment. [D2]
- 9. When assessing social interactions and relationships, it is important to:
  - Use tactile stimulation paired with auditory stimulation to elicit social responses
  - Consider lighting and positioning of both child and evaluator to maximize the child's use of vision for social interaction during assessment
  - Allow more time for the child to respond and not try to anticipate the response
  - Give the child time to initiate contact [D2]
- 10. It may be useful to videotape children in typical situations to obtain and preserve baseline behavior, and to measure changes over time in the following:
  - Parent-child interactions in play situations
  - Parents' child-directed speech
  - Parents' style of verbal interaction with regard to directiveness
  - Sibling interactions
  - Peer interaction in child care and other early childhood settings [D2]

#### ASSESSING ORIENTATION AND MOBILITY

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

This section addresses general considerations specific to assessing orientation and mobility in young children with vision impairment.

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.

- Orientation: the process of utilizing sensory information to establish and maintain one's position in the environment.
- Mobility: the process of moving safely, efficiently, gracefully, and as independently as possible within one's environment.

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
- Use of residual vision for mobility
- Body image (the ability to name and locate 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)

Basis for the recommendations about assessment of orientation and mobility

The recommendations in this section for assessing orientation and mobility are based primarily on panel consensus opinion. No studies meeting the criteria for this guideline were identified for this topic. In the panel's opinion, these recommendations reflect appropriate practices for assessing children with vision impairment, and are generally consistent with the scientific knowledge in this field.

# **Recommendations (Assessing Orientation and Mobility)**

General approach for orientation and mobility assessment

- 1. 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 the amount of residual vision. Formal orientation and mobility assessment is recommended when the family or other team members request an evaluation or when:
  - A specific orientation and mobility need is identified, such as when the child:
    - Demonstrates a desire to travel independently around his environment but needs assistance to do so safely
    - Demonstrates marked reluctance to move independently
    - Is having difficulty developing independent movement skills
    - Demonstrates unsafe independent travel skills (e.g.,not stopping at the top of stairs)
  - A child who has 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 [D2]
- 2. When a child has significant early vision loss, it is recommended that formal orientation and mobility assessments begin when the child is approximately 6 months old. [D2]
- 3. It is important to include parents in the assessment process because they can provide important information about the child as well as information about the strengths/abilities and needs of the family. [D2]

Conducting the orientation and mobility assessment

- 4. It is important that the orientation and mobility assessment be conducted by a qualified professional with experience and expertise in working with young children with vision impairment and their families. [D2]
- 5. When conducting the orientation and mobility assessment, it is important to:
  - Avoid doing the entire assessment in one session because the child may tire and do poorly with gross motor items

- Recognize the developmental differences between children who have low vision (useful travel vision) and blind children (those without useful travel vision)--what may be appropriate for one child may not be appropriate for another [D2]
- 6. It is important that the professional conducting the assessment:
  - Be sensitive to the comfort level of the child
  - Be familiar with developmental patterns of typically developing children, as well as both low vision and blind children
  - Be sensitive to the comfort level of the parent, especially around issues of independence and safety [D2]
- 7. It is important that the setting for assessment:
  - Have minimal distractions
  - Include a variety of textures and environmental features (stairs, doors, and wide, narrow areas)
  - Have both a familiar and an unfamiliar area
  - Have variable or a variety of lighting
  - Use toys or mobility devices familiar to the child, as well as some unfamiliar items [D2]

# Components of the orientation and mobility assessment:

- 8. It is important that the orientation and mobility assessment consider the child's home and other natural environments, and the potential for opportunities to develop and use independent travel skills. [D2]
- 9. Important components of an orientation and mobility assessment include:
  - Information about the eye condition and functional implications of that type of vision loss
  - Any important health/developmental/background information that may affect the child's development, including recent and updated reports regarding the child's eye health status
  - How the child uses vision (indoors, outdoors, and in familiar and unfamiliar areas)
  - Ability to generalize and use the skill in a natural, functional manner
  - Amount of residual vision
  - Basic auditory functioning
  - Basic gross motor functioning

- Ability to use tactile cues
- Any demonstrated compensatory skills
- Basic concept development including body parts, positional concepts, and spatial concepts (as appropriate for the child's developmental age)
- · Amount and type of independent travel
- Amount and type of guided travel
- Concerns raised by the child's parents or others working with the child [D2]
- 10. It is important to assess not only the child's ability to demonstrate a skill in isolation but also the child's ability to generalize and use the skill in a natural and functional manner. [D2]

# ASSESSING THE NEED FOR ASSISTIVE TECHNOLOGY DEVICES

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

This section addresses general considerations specific to assessing the need for assistive technology devices in young children with vision impairment.

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 device than without it.

Assistive technology devices can be either low technology or high technology. High-technology devices typically are more complex 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.

Assistive technology assessment includes the evaluation of the needs of a child with a disability, including a functional evaluation of the child in the child's customary environment. Customary environments are those settings that are natural or normal for the child's same age peers who have no disabilities and in which the child would typically use the AT device. Customary environments generally include both home and community settings in which children typically participate.

# Basis for the recommendations in this section

The recommendations in this section on considerations for assessing the need for assistive technology are based primarily on panel consensus opinion. No studies meeting the criteria for this guideline were identified for this topic. In the panel's opinion, these recommendations reflect appropriate practices for assessing children with vision impairment and are generally consistent with the scientific knowledge in this field.

#### **Recommendations (Assessing the Need for AT Devices)**

Importance of assessing AT needs of children with vision impairment

 It is recommended that the need for assistive technology be considered for all children with vision impairment and that this need be reassessed on an ongoing basis. [D2]

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 (including vision and hearing), social/emotional, communication, or adaptive development.

- 2. It is important to consider the need for AT when:
  - Other intervention approaches for specific needs are not sufficient to achieve the desired outcome
  - A situational or environmental change occurs (e.g., entry into a day care center)
  - There is a change in the child's needs/skills
  - There is a change in technology [D2]

Components of the AT assessment process

3. It is important to include family in all aspects of the assessment process and to obtain information from the parents about the child's needs and about their attitudes about the use of AT. [D2]

- 4. In determining which specific AT devices will help a child, it is important that the assessment begin with information about the current needs of the individual child and family, including:
  - The child's visual functioning
  - The child's cognitive, motor, and language abilities
  - The specific needs and preferences of the child and family
  - 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 [D1]
- 5. It is important that the professional conducting the assessment gather information from the family and other members of the team about the following:
  - A description of the environment(s) that the AT device will be used in
  - A description of family members' activities within their daily routines and the child's current level of independent participation
  - The specific tasks/activities that the AT device will address [D1]
- 6. It is recommended that an assessment of the need for AT devices include assessment of the need for AT services to support the child and family's use of the AT devices being considered. Services can include:
  - Customization or fitting of the device to the child in the natural setting
  - Training for the family, caregivers, and other team members to use the device
  - Training the child to use the device
  - Integration of AT device into other services [D2]
- 7. It is important that the child's vision professional be consulted when assessing the need for and appropriateness of AT devices. [D2]

# Selecting AT devices

- 8. It is important that any assistive technology being considered have purpose and meaning for both the child and the parent (Table 18, page 99). It must be practical and feasible for the family to use. Assistive technology provides no benefits if it is not used. [D2]
- 9. When considering options for assistive devices, it is important to identify options that can help the child achieve the highest level of independence. In general, acceptable low-tech options, if available, often allow the child to develop more independent function. [D1]

# Professionals conducting the AT assessment

- 10. It is essential that the professionals assessing the need for assistive technology:
  - Be knowledgeable about assistive technology in general as well as the particular 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 assistive technology services (training and customization) to support the use of any AT devices that might be recommended [D2]
- 11. It is important that the child's vision professional be consulted and that the appropriate AT be individually assessed for the child's current needs. [D2]

# Table 18: 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 mobility purpose?
- Is the child able to/will the child use the device in a manner safe to self and others?
- Have limitations been established to assure safe use of the device?

# Table 18: Questions to Ask When Evaluating Assistive Technology

# 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 for the child and family?

#### 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)

#### **WORKING WITH THE FAMILY**

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

Topics in this section include:

- Informing the Family About the Diagnosis
- Assessing the Resources, Priorities, and Concerns of the Family

Basis for the recommendations in this section

The recommendations in this section about considerations when working with the family are based primarily on panel consensus opinion. No studies meeting the criteria for this guideline were identified for this topic. Many of the recommendations are based on findings from review articles that were specific to issues related to family assessment. In the panel's opinion, these recommendations reflect appropriate practices for assessing children with vision impairment and are generally consistent with the scientific knowledge in this field.

#### **Informing the Family About the Diagnosis**

The following factors may affect parents' response when learning that their child either has or is suspected of having vision impairment:

- Characteristics of the child's condition
- Certainty of the diagnosis and prognosis
- Preexisting family factors (e.g., previous knowledge and beliefs about the condition, family circumstances, and family stressors)
- The quality of the information provided

Other factors that may influence parents' response to the diagnosis relate to the setting and manner in which the diagnosis is communicated. Parents' preferences for receiving the news about the diagnosis generally include:

- Speaking in a private setting with both parents in person rather than by telephone
- Considering the whole child, rather than focusing only on the limitations associated with the condition
- Being supportive and sensitive to the feelings of the parents

# **Recommendations (Informing the Family About the Diagnosis)**

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

- 1. As soon as there are indications that a child either may have or be at significant risk for vision impairment (Table 7, page 42), it is important for the physician to communicate this information to the parents and make a referral to an appropriate ophthalmologist or optometrist. [D2]
- 2. It is important for all parents and other primary caregivers of young children who either have or are suspected of having vision impairment to receive accurate information about their child's condition in order to allow them to:
  - Function as active partners with health care and other providers in monitoring the overall development and health of their child
  - Have informed and reasonable expectations about their child's development
  - Make informed decisions about their child's medical and educational services
  - Become informed advocates for their child [D2]

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

- 3. When the family is informed that the child either has or is at high risk for vision impairment, it is important that this information be conveyed in a sensitive and caring way that supports the family. [D2]
- 4. It is recommended that when a young child is either at high risk for or suspected of having vision impairment, the physician share this information in person with the parents and every effort be made to inform them in private rather than in the presence of strangers. Parents should be given the opportunity to have additional support present if they wish. [D2]
- 5. For the physician "breaking the news" to parents about their child's potential for ongoing health and developmental problems or disabilities, it is important to recognize that:

- Parents need to be able to hope and believe in a positive future for their child
- It is impossible in most circumstances 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. Many parents will understand that it may not
  be possible to know or predict the infant's future outcomes [D2]
- 6. When providing information about their child to the family, it is important to allow parents time to absorb the information provided and to follow up shortly after to discuss questions parents may have. [D2]
- 7. 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. For example, parents may be concerned because they may believe the diagnosis implies that the child will never see, never function independently, and always have to attend a special school. Therefore, it may be important to discuss with the parents not only what a diagnosis means but also what it does not mean for their child. [D2]
- 8. When a child is either at high risk for or 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. [D2]
- 9. When conveying news that a child either has or is at high risk for vision impairment, it may be helpful to use an approach such as **PACE**:
  - Plan the situation and setting in which the family is informed
  - Assess preexisting family factors such as the parents' previous knowledge and experience about vision impairment
  - Choose helpful informing strategies that meet the needs of the family
  - Elicit feedback from the family [D2] (Gawick 1995)
- 10. When choosing the types of information and strategies for delivering news to the family that their child either has or is at high risk for vision impairment, it is important to be respectful and to provide understandable information. [D2]

# Communicating with the family

- 11. When communicating with the family about a child's disability or risk for a disability, it is important for all professionals to:
  - 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, and avoid negative labeling of the condition or the child
  - Refer to the child and the parents by name
  - 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 [D2]
- 12. 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 being informed that their child has significant vision impairment. This may be a reaction to their feelings about their hopes for the future of the family and the child. [D2]

# Responding to the needs of the family

- 13. It is important that professionals listen to the reactions of family members after delivering news about a child's condition so that appropriate support and information can be provided. It is important to understand that not all families will have the same reaction. [D2]
- 14. It is important that parents, after learning that their child either has or is suspected of having vision impairment, have opportunities to be given enough time to ask questions and to discuss concerns with a health care professional in an unhurried manner. [D2]
- 15. It is important to recognize that:
  - Parents may react differently to an uncertain prognosis about the child's developmental potential; some parents may find uncertainty stressful, but for others it provides hope
  - Physicians attempting to prepare parents for the worst may be inadvertently eliminating hope and/or setting up an adversarial relationship between the physician and the parents [D2]
- 16. 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. [D2]

Understanding that parents may feel they are responsible for the vision impairment

17. When informing parents that their child may have significant vision impairment, it is important to recognize that they may 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 etiology (cause) of the vision impairment and, to the extent that it is truthful, inform the parents that it is not the result of something the parents did or did not do. [D2]

Factors that may affect the family's response

- 18. There are specific factors that may affect how the family responds when learning that the child either has or is suspected of having vision impairment. These factors may include:
  - What the family knows/believes about the condition
  - Certainty of the diagnosis and prognosis
  - Preexisting family factors, such as condition of the mother and infant at the time parents are informed or current family stressors
  - The setting in which the family was informed
  - The manner in which health care professionals initially informed them
  - The quality of the information provided [D2]
- 19. 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 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 parents' opinions and feelings
  - Recognize that parents are valuable observers who have knowledge about their child that needs to be considered when planning their child's care
  - Provide opportunities for 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
  - Offer opportunities for parent-to-parent support [D2]

- 20. It is important to recognize that parental satisfaction with being told about a child's disability may be higher if the parents feel that the professionals listened to and acted upon parental concerns before the diagnosis was made. [D2]
- 21. It is important to recognize that the values and beliefs of family members may affect how they respond when told that the child has vision impairment. Family members' beliefs and attitudes might influence how members perceive or feel about:
  - The cause of the disability
  - How the child will be valued and treated by others
  - What role a child with a disability can or should play within the family and within the larger society
  - The possible role of prayer or other spiritual intervention
  - Allocation of responsibility for daily care of the child
  - Allocation of decision-making responsibility regarding the child
  - Informal family support available to and accepted by the family
  - Attitudes toward health care and service providers, including level of authority granted to professionals and their opinions
  - Preferred patterns of communication such as:
    - Indirect or direct communication between parent and health care and other service providers
    - Level of detail desired
    - Appropriateness of eye contact
    - Level of formality considered appropriate
    - Acceptable boundaries for expressing emotion [D2]

# Assessing the Resources, Priorities, and Concerns of the Family

Assessment of the family's resources, priorities, and concerns is an important component of planning interventions that will benefit the child and family. Intervention services are most effective if they are matched to the strengths and needs of the individual family and child. This is important because the child's needs can be understood only within the context of the family and the family's culture. Furthermore, the resources, priorities, and concerns of the family may be more predictive of outcome than the child's needs are for both parent-related outcomes and child outcomes.

# Family interaction patterns

A variety of factors may influence family interaction patterns. Some of these factors are generally relevant to all children and families regardless of a child's disability or risk status. For example:

- The style of the parent-child interaction (e.g., encouraging, affectively warm, nonintrusive, appropriately structured, discourse-based, and developmentally sensitive patterns of caregiver-child interactions).
- The extent to which the family provides the child with diverse and appropriate experiences within the surrounding cultural, social, and physical environment (e.g., the frequency and quality of contacts with different adults, the variety of toys and materials available, and the stimulation value of the general environment).
- The way in which the family ensures the child's health and safety (e.g., providing adequate nutrition and a safe home environment, obtaining immunizations and routine and specialized health care) (Guralnick 1997).

For a child with established disabilities, a variety of factors may interfere with a family's ability to establish patterns of interaction that optimally facilitate and support the child's development. Some of these factors may include:

- Lack of information about the child's health and development
- Preconceived notions/beliefs about the condition
- Interpersonal and family stress
- Lack of resources or support
- Language or cultural considerations
- Threats to confidence in parenting skills (Guralnick 1997)

There are important factors that may impact the family's response to potential stressors. The extent to which stressors actually affect the family patterns depends on the magnitude of the stressors and the characteristics of the family. Not all families are the same. In general, those with adequate coping resources are less likely to regard potential stressors as stressful. Research suggests that the most important social support is the existence of a confiding relationship or strong ties, usually within the family (Knussen 1992).

For mothers of children with developmental disabilities, family characteristics and processes (family cohesion, level of family support, and mother-child interactive behaviors) are often more predictive of parenting and child-related stress than specific child characteristics are (Warfield 1999). Family processes

are also generally more predictive of adaptive development such as growth trajectories in communication, daily living, and social skills, than are other measures such as maternal education or psychomotor measures, during infancy (Hauser-Cram 1999).

While the availability of strong family support may be an important factor in a family's inventory of coping resources, nonsupportive behavior from family, friends, or service providers may be "more than the loss of a protective factor and might actually become a risk factor" (Patterson 1997). Nonsupportive behaviors reported by parents can include:

- Comparisons with other children
- Focusing only on what is "wrong" with the child
- Questioning why a child cannot achieve developmental milestones
- Assuming lower expectations than a child's potential
- Offering unsolicited and inappropriate advice
- Blaming parents for the cause of the condition
- Criticizing parental caregiving
- Pitying remarks concerning the child or the parents

# The family assessment

A family assessment is designed to help identify the family's resources, priorities, and concerns in order to be able to develop intervention plans that are meaningful and relevant to the family. 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

It is important for professionals to recognize that some families may be uncomfortable participating in a family assessment and may interpret the assessment as a message that something is "wrong" with their family functioning. While some parents may find it helpful, others may find it intrusive.

Conducting a family assessment requires skill and practice. Many professional assessments of family needs are weakly correlated with parents' assessment of their needs. In family-oriented assessment, the task for professionals is to

objectively and sensitively help parents articulate the needs and goals of the family (Krauss 1997).

# Recommendations (Assessing the Resources, Priorities, and Concerns of the Family)

Importance of assessing the family

1. It is recommended that the family of a child with vision impairment be encouraged to participate in a family assessment process. This is important because the information gathered through this process can assist with planning effective intervention strategies and goals/objectives. [D2]



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

# Components of a family assessment

- 2. It is recommended that assessment of the family's resources, priorities, and concerns 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, both short- and long-term, for the child
  - Family composition (including siblings and extended family)
  - Family demographics, education, and 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 interpersonal and problem-solving styles and patterns
  - Caregiving skills and sharing of the caregiving responsibilities

- Parenting styles
- Issues related to nonsupportive behaviors of family members, friends, and community [D2]
- 3. When assessing the family's resources, priorities, and concerns, it is important to recognize the role of the family's cultural and ethnic background. Cultural background may affect:
  - Who within the family is 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 and ease in using different types of information
  - The family's comfort with expressing needs [D2]

# Family assessment approaches

- 4. Family assessment involves respecting differences in family styles and goals. It is important that professionals conducting family assessments:
  - Develop a collaborative relationship with parents involving mutual respect
  - Listen to parents nonjudgmentally
  - Be interested in and value parents' input [D2]
- 5. It is recommended that information gathered in the family assessment be used to help families:
  - Establish and articulate needs
  - Develop realistic priorities
  - Become aware of available services for the child and sources of family supports, both formal and informal
  - Obtain specific information about expected developmental patterns, progress of educational and therapeutic interventions, and any special problems likely to be encountered [D2]
- 6. It may be useful to use a specific measurement tool, such as the Parenting Stress Index, the Coping Inventory, or the Family Resource Scale, to measure parental stress that may impact family well-being. [D2]

- 7. Because some families may be uncomfortable with participating in a family assessment, it is important for professionals to:
  - Establish a collaborative relationship with parents
  - Listen effectively and nonjudgmentally to family-identified needs
  - 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 adequacy of any particular family
  - Be familiar with the questions to be asked during the assessment and sensitive to the parent's level of comfort with the questions
  - Be appropriately trained to use any specific tests or protocols for the family assessment [D2]
- 8. It is important to recognize that family strengths and needs may change over time. Some families may require more frequent family assessments than do other families. It is recommended that there be ongoing family assessment based on the individual needs of the family. [D2]
- 9. It is important that professionals provide an appropriate setting and support individualized to the family's needs to promote the assessment process. [D2]

# CHAPTER IV: INTERVENTION

# INTERVENTION METHODS FOR YOUNG CHILDREN WITH VISION IMPAIRMENT

Topics included in this chapter

- General Approach
- Medical and Surgical Interventions to Improve Vision
- Intervention Focused on Improving Visual Function
- Orientation and Mobility Training Interventions
- Interventions for Specific Developmental Domains
- Assistive Technology
- Alternative Intervention Approaches

Overview of the evidence for the recommendations in this chapter

An extensive literature search and review were conducted to identify scientific studies addressing intervention topics of interest for this guideline. For most of the topics, only a small number of studies were found that met the criteria for evidence. For some of the topics, no studies were found. For a few topics, such as medical/surgical interventions, a specific literature search was not conducted because this was considered outside the primary scope of the guideline. Information from other sources, such as review articles, was often considered, but these generally do not meet the criteria for evidence. Therefore, many of the recommendations in this chapter are based on panel consensus opinion. Because of the limitations of the efficacy evidence for the topics of interest, additional evidence criteria were developed, and some of the recommendations are supported by studies that provide information about the developmental characteristics of young children with vision impairment.

#### **GENERAL APPROACH**

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

This section presents general approach recommendations for planning and implementing interventions for young children with vision impairment including:

- General Considerations for Planning and Implementing Interventions
- General Approach for Evaluating Intervention Options
- Involving the Family in Planning and Implementing Interventions
- Providing Support to Parents and Families

Basis for the recommendations in this section

The recommendations about the general approach for interventions for young children with vision impairment are a combination of evidence-based and panel consensus recommendations. Many of the recommendations in this section relate to approaches that generally do not lend themselves to controlled scientific studies. In the panel's opinion, these recommendations reflect appropriate practices for children with vision impairment and are generally consistent with the current knowledge in this field.

# **General Considerations for Planning and Implementing Interventions**

The general considerations for planning and implementing interventions for children with vision impairment are, for the most part, similar to the considerations involved in intervention planning for children who have any condition. Decisions regarding intervention for a particular child are linked closely with that child's specific condition and assessment results so that the intervention can be individualized to the child's strengths and needs. The family's strengths, needs, and priorities are also considered.

No single intervention approach or strategy will be appropriate for all children with vision impairment. For some children, the vision impairment will be identified during the newborn period, and therefore the child and family may enter into an intervention program at a very young age. Other children will not

be identified until later. Some children may have early indicators of a potential problem that requires ongoing monitoring and surveillance before determining the need for intervention. For some children, there may be a treatment (surgery or glasses) that will correct or improve the child's visual abilities; others may have vision impairment that is not correctable. The specific type and frequency of the intervention and the appropriate time to initiate the intervention will be determined based on the needs of the child and the family.

# **Recommendations (General Considerations for Planning and Implementing)**

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 speed the child's overall development and lead to better long-term functional outcomes.

[A] (Cioni 1997, Correa 1984, Harley 1987, Mercuri 1997, Pinto-Martin 1996) [Bdc] (Levitzion-Korach 2000, Parsons 1986, Troester 1994)



Early Intervention Policy 
Children's eligibility under the Early Intervention Program can be established through either the presence of a developmental delay that meets the state definition of developmental delay or the presence of 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.

Individualizing interventions based on information from the assessment

- 2. It is recommended that the use of any intervention for children who have noncorrectable vision impairment be based on an assessment of the specific strengths and needs of the child and the resources, priorities, and concerns of the family. This is important because:
  - Young children with vision impairment differ in terms of their individual strengths and needs, as well as in their responses to specific intervention methods or techniques.
  - Children have different family situations, and some families may need more support than others. [D2]

Early Intervention Policy \* When children are found 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 and the services needed by the child and family. The services included in the IFSP are provided at no cost to parents.

The type, intensity, frequency, and duration of early intervention services are determined through the IFSP process. All services in the IFSP must be agreed to by the parent and the Early Intervention Official (EIO). When disagreements about what should be included in the IFSP occur, parents can seek due process through mediation and/or an impartial hearing.

The IFSP must be reviewed every six months and evaluated annually. Information from ongoing assessments should be used in IFSP reviews and annual evaluations. An IFSP may be amended any time the parent(s) and the EIO agree that a change is needed to better meet the needs of the child and family. (see Appendix D for EI Program information.)

# Considering the child's health status

3. Before initiating intervention for a young child with vision impairment, it is important to consult with the child's primary health care physician to obtain all relevant information about the child's health status, including current eye reports and any associated health conditions that may affect intervention activities, and to ensure that there are no contraindications to the intervention. [D2]

**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.

#### Selecting intervention strategies and targets

4. For young children with vision impairment, both the nature of the intervention and the child's developmental and health status are factors that may impact the outcome of the intervention. This is important to understand and consider when selecting intervention strategies and the expectations for intervention, and when evaluating the effectiveness of intervention approaches. [D2]

- 5. It is important that functional visual skills (how the child uses vision) be assessed and interventions be developed 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 ID21
- 6. A comprehensive model of intervention strategies is recommended for most young children with vision impairment. A comprehensive model includes the opportunity for home-based and/or community/center-based services as well as family support services. It is important to develop strategies specific to the needs of the child and family. [D2]

**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 also include typically developing peers.) Family support groups are also available.

- 7. It is important that intervention strategies and outcomes:
  - Be developed with the participation of the parents
  - Be sensitive to the particular culture of the family
  - Take into consideration the child's health status
  - Assist the family's and child's integration into the community
  - Maximize the natural opportunities [D2]
- 8. When deciding either 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 the available alternatives for the child and family
  - The developmental needs and skills of the child

- Current needs based on context and environment
- Resources, priorities, and concerns of the family
- Potential risks and harms associated with the intervention [D2]

Developing the overall intervention plan and coordinating activities

- 9. It is important that an overall intervention plan be developed for the child (with participation by both professionals and parents) and that this plan:
  - Defines desired outcomes for the intervention program and identifies objective criteria for outcomes measurement
  - Ensures all individual intervention components are compatible and coordinated to avoid any potential conflicts, and ensures they are consistent with the desired intervention outcomes for the child and family
  - Provides for baseline and ongoing assessment of the child's progress, and specifies the methods, schedule, and criteria for such periodic assessments
  - Provides for appropriate modification or discontinuation of the intervention based on periodic assessment of the child's progress [D2]

Early Intervention Policy ❖ In the Early Intervention Program, the Individualized Family Service Plan must be in writing and have the required components specified in program regulations. (see Appendix D for Early Intervention Program regulations.)

Determining the intervention setting

- 10. When determining the most appropriate settings for interventions, it is important to consider the following:
  - 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
  - The ability to modify the setting to adapt to the needs of the child

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- The child's cognitive, social/emotional, communication, and motor development (Is the setting developmentally appropriate?)
- Health status and associated health conditions [D2]
- 11. When a change in the intervention setting is being considered, it is important to address any concerns parents may have about the proposed change (e.g., from the home to more community-based or group settings). [D2]

Early Intervention Policy ❖ Under the Individuals with Disabilities
Education Act and the New York State Public Health Law, 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 mean settings that are natural or
normal for typically developing same-aged peers.

Determining the frequency and intensity of the intervention

- 12. When determining the frequency and intensity for interventions, it is important to consider:
  - The needs of the child and family as expressed in the desired outcomes for various interventions
  - The child's ability to engage in and tolerate the intervention
  - The techniques that are appropriate to address the child's needs
  - The child's progress
  - The setting where intervention will be provided
  - The balance of intervention with child and family routines and schedules
  - The severity of the condition [D1]

Ongoing monitoring and modification of the intervention

13. It is recommended that any intervention be tied to ongoing assessment and modification of intervention strategies as needed. [D2]

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. Modifications 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 upon by the parent and EIO and included in the IFSP.

- 14. It is recommended parents be informed that the types of intervention and frequency of intervention may change over time. It is important for parents to understand that interventions may need to be adjusted based on ongoing reassessment of the child's progress and needs. Adjusting the intervention might mean increasing or decreasing the frequency or intensity, or changing some aspect of the approach or the setting. [D2]
- 15. 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 shows some progress, but target objectives are not achieved after an appropriate trial period
  - The child's behavior or health status unexpectedly changes
  - The intervention setting changes (moving from the home to a preschool setting)
  - Family priorities change [D2]
- 16. When evaluating the effectiveness of interventions and the child's progress, it is important to:
  - Measure a broad range of functional and developmental outcomes, rather than look only at isolated quantitative measurements (e.g., visual acuity) that may not be representative of the child's level of visual functioning
  - Consider both quantitative and functional measures [D2]

Using periodic assessments to monitor progress and modify the intervention plan

- 17. In addition to ongoing monitoring, it is recommended that periodic reassessment of the child's progress and overall developmental status be performed at least once every six to twelve months. As part of the periodic reassessment of the child, 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 [D2]
- 18. It is recommended that the initial and periodic reassessments of the child's progress include:
  - Objective tests of the child's development (Table 14, page 72)
  - Direct observation of the child's developmental/functional skills by a professional with vision impairment experience
  - General impressions from parents and professionals working with the child regarding the child's developmental progress and adaptive independent functioning [D2]
- 19. When using objective tests to assess the child's developmental progress, it is important that:
  - The tests be given at the beginning of the intervention program and then at scheduled periodic intervals
  - The same tests be used for initial and periodic assessments (unless changes in the child's developmental level require the use of different tests)
  - The tests be developmentally appropriate and, when possible, cultural factors considered
  - Test results be analyzed longitudinally to see patterns of change over time
  - Test results be used in conjunction with other information to help determine if the intervention program is effective, if interventions may need to be modified or discontinued, and/or if other interventions may be needed [D2]

Evaluating the child's progress and effectiveness of the interventions

- 20. When evaluating the child's progress 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
  - When 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) [D1]
- 21. It is important to recognize that if periodic assessments suggest a child's developmental skills and overall functioning are not progressing as expected, it is possible that:
  - The type of interventions used are not effective for that child
  - The assessment methods used to determine the strengths and needs of the child might not be appropriate or might not adequately reflect progress that is being made by the child (e.g., the assessment tool may not assess tasks in small enough steps for a young child to show progress)
  - The frequency or intensity of the interventions are not sufficient to show any effect
  - Some other health or developmental factor is interfering with the child's development in this area [D2]

# Collaboration, coordination, and integration

- 22. When an intervention program is being planned, it is recommended that techniques and approaches be coordinated, integrated, and collaborative across all individuals working with the child and family, and that careful consideration be given to integrating the intervention approaches and/or components to ensure they are compatible and complementary. [D2]
- 23. It is important for all team members, including 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. [D2]

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24. It is recommended that the child's primary health care provider receive ongoing progress reports that include information regarding the child's developmental progress that can help the health care provider make ongoing treatment decisions. [D2]

Early Intervention Policy ❖ In the Early Intervention Program, the results of an evaluation, the plan for services, and progress reports may be shared with the child's primary health care provider(s) with parental consent.

Qualifications and experience of professionals providing interventions

- 25. 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 undergo 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 [D2]

# **General Approach for Evaluating Intervention Options**

Many different types of intervention approaches may be considered for a young child who has vision impairment. The intervention will depend on the nature and severity of the vision impairment, and on the strengths and needs of the child and family.

In addition to the interventions specific to correcting or improving/maintaining the child's vision, most young children with significant vision impairment will also need interventions to support their development in other areas such as gross and fine motor skills and communication.

Some approaches, such as physical therapy, occupational therapy, and speech-language therapy, might be considered standard or traditional. There is also a diverse collection of nontraditional therapeutic models and techniques that is sometimes referred to as "complementary" or "alternative" (light therapy, hyperbaric oxygen treatment) that may be promoted as treatments for vision

impairment. These approaches vary greatly in how commonly they are used, the potential benefits and harms, the time commitment required (intensity), availability, and cost.

In today's world of instant information through the Internet, parents and family members are likely to seek information about their child's disability, and they are likely to find many sources of information about intervention options, including tempting claims that a particular intervention will lead to a dramatic improvement in the child's condition. Parents need to understand how to evaluate this information, and professionals who want to work effectively with the parents need to understand how to help them make intervention decisions.

# **Recommendations (Evaluating Intervention Options)**

Considering evidence about effectiveness in selecting interventions

- It is important to recognize that parents may seek 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 for both professionals and parents to evaluate the accuracy of such information, rather than to take at face value claims of effectiveness. [D2]
- 2. When determining appropriate interventions for young children with vision impairment, it is important to understand that some interventions may not have established efficacy for improving either the child's vision or functional skills, but may still benefit the child if they provide physical activity, opportunities for social interaction, or otherwise facilitate the child's overall development. These interventions might be considered to supplement or complement those interventions that focus more specifically on the vision impairment and developmental skills. [D2]
- 3. It is important to recognize that regardless of the specific interventions being considered for a particular child, the decision-making process is generally the same. Tables 19 and 20 (pages 126 and 127) suggest questions to ask when evaluating various interventions and service providers. [D2]

# **Table 19: 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 impairment?
- 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 20: 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 are required?
- How are the interventions structured (one-on-one with the child, peer groups, parent-child instruction)?
- In what kind of setting(s) is the intervention provided (home, office, clinic, or 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 with 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 staff?
- Are parents involved with planning as part of the intervention team?
- Is there a parent education/parent training component?
- How much and what kinds of opportunities for involvement are available to 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?

- 4. When evaluating information about the effectiveness of interventions, it is important for professionals and parents 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 case reports about the effectiveness
    of intervention methods can be misleading because they often do not
    adequately control for factors that might bias 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 [D2]

The role of professionals when helping parents make decisions about interventions

- 5. It is important for professionals to ensure that families have information about and access to standard services such as physical therapy, occupational therapy, and speech therapy, and are actively involved in intervention decisions. [D2]
- 6. It is important that professionals and parents work together to make informed decisions about interventions for the child. When talking to parents about intervention options, the role of the professional includes:
  - Being supportive and helpful
  - Being knowledgeable about standard intervention methods as well as new or alternative interventions (potential benefits and limitations, time commitments, possible risks and costs) and ensuring that accurate information is provided
  - Being open to discussing alternative interventions whenever parents ask questions about such methods and scheduling adequate time when intervention options are discussed with parents
  - Giving informed opinions to parents about the possible efficacy and potential side effects of the interventions being considered, and providing information about any adequate scientific evidence regarding these issues [D2]

7. When considering any intervention, it is recommended that parents and professionals together address the questions in Tables 19 and 20 (pages 126-127) as an aid when making decisions about the use of a particular intervention. [D2]

# **Including the Family in Planning and Implementing Interventions**

As for all children, the family plays the primary role in all aspects of caring for and raising a child. For children with vision impairment, the family also plays a vital role in planning, supporting, and providing intervention for the child. Including parents and family in decisions about interventions is a necessity. The needs of the child are best understood within the context of the family and the family's culture. Intervention services are most effective if they are matched to the strengths and needs of the child as well as to the resources, priorities, and concerns of the family (see page 106).

The assessment and intervention process may 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 for children with vision impairment focus on the parents rather than the infant. Interventions may focus on the parents' need for information or the need for family support. Even with interventions that involve a professional working directly with the child, informal or formal parent training may be an important component of the intervention.

# **Recommendations (Including the Family in Planning/Implementing Interventions)**

*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 [D2]

- 2. In order to encourage, support, and facilitate parent participation, it is recommended that:
  - Parents be involved in determining their own ability, availability, and willingness to participate in the intervention
  - Professionals provide ongoing opportunities for the family to express their concerns and needs regarding their participation
  - Both parents and professionals set realistic expectations and consider/be respectful of the other demands and priorities of the family [D2]

## Level of parental involvement

- 3. 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 be made on a case-by-case basis and consider:
  - The parents' level of interest, availability, and ability to participate in the intervention
  - The parents' comfort with the intervention
  - The impact that the level of participation has on the level of parent stress and the effect on other family patterns of interaction/family dynamics
  - Characteristics of the child's home environment
  - The availability of training and professional support [D2]
- 4. A home program carried out by parents under the direction of a qualified professional can be an important part of the overall intervention.

  [B] (Behl 1993, Harley 1987, Leguire 1992)
- 5. It is important to note that services in and of themselves may be stressful to the family. [D2]

## Considering the cultural context of the child and family

- 6. It is important to remember that family members' beliefs and values (their cultural context) may affect many different aspects of their relationship with the child as well as their relationships with professionals (Table 21, page 131) [D2]
- 7. It is essential to consider and respect the family's culture and primary language when providing interventions for children with vision impairment. It is recommended that:

- Interventions be provided in the primary language of the child and family whenever possible
- The professional consult with someone familiar with the culture and language of the family as needed
- If an interpreter assists in the intervention process, the interpreter be trained to provide culturally and linguistically accurate interpretations relevant to the intervention [D2]

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.

# Table 21: The Cultural Context of the Family: Influence of Family Beliefs and Values

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 when 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

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- Patterns of feeding and holding a young child
- Preferred sleeping patterns for the child
- 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 or approach to interacting with professionals

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Role of the professionals working with the parents

- 8. It is important for professionals to work with the parents to determine appropriate and acceptable ways to include the parents/family and other caregivers in facilitating progress towards the intervention goals. [D2]
- 9. It is important that professionals are available to respond to parents' questions and needs. It is important that this be ongoing because the questions and needs will change as the child develops. [D2]

**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.

- 10. It is recommended that the professional:
  - Work collaboratively with the parents to develop the intervention program
  - Elicit observations from the parents regarding the child's functioning
  - Share regular progress reports with the parents
  - Give parents regular feedback based on direct observation of the child
  - Consider the cultural perception of the family's role in intervention [D2]
- 11. It is recommended that professionals 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. [B] (Behl 1993, Harley 1987, Leguire 1992)

#### Parent education and training

12. It is recommended that structured parent education, including appropriate parent training, be part of any intervention program.

[B] (Behl 1993, Harley 1987, Leguire 1992)

- 13. It is important to provide parents with information about:
  - Intervention options 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 [D2]

- 14. Important components of parent training include:
  - Instructing parents in specific techniques focused on providing opportunities for increasing the child's personal independence and functioning as a part of the family
  - 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 [D2]

# **Providing Support to Parents and Families**

Family support is a broad concept that includes both informal and formal support in both planned and naturally occurring interactions. Family support processes are complex and may affect the behavioral outcomes of parents, child, and family directly or indirectly. 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, perhaps mediated through the parent/caregiver sense of well-being and interaction styles with the child. Intervention services, including family support services, are most effective if they are matched to the needs of the individual family.

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

## **Recommendations (Providing Support to Parents and Families)**

- 1. It is important to recognize that family support includes:
  - Both formal and informal support
  - Planned and naturally occurring interactions that may be related directly and/or indirectly to child, parent, and family functioning [D2]
- 2. When providing support to families, it may be useful to consider ways of helping the family mobilize informal support networks rather than to rely solely on a formal approach to support. [D2]
- 3. 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. [D2]



Early Intervention Policy & Individual family counseling and family support groups are early intervention services.

- 4. If professional support is provided, it is recommended that this support be in response to an indicated need for particular kinds of information or resources and provided in a way that mirrors features found in informal support networks. [D2]
- 5. 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. [D2]
- 6. 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. [D2]

#### MEDICAL AND SURGICAL INTERVENTIONS TO IMPROVE VISION

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

 $[d_c]$  = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

Topics covered in this section:

- General Considerations for Medical and Surgical Interventions
- Optical Correction

Basis for the recommendations in this section

The recommendations for medical/surgical interventions for young children with vision impairment are primarily panel consensus recommendations. Review articles and other sources of information were identified and considered, but a specific literature search for evidence was not conducted for this topic because it was generally considered outside the primary scope of the guideline. In the panel's opinion, these recommendations reflect appropriate practices for providing interventions to young children with vision impairment and are generally consistent with the scientific knowledge in this field.

### **General Considerations for Medical and Surgical Interventions**

During infancy and early childhood, there is a unique window of opportunity for influencing the child's visual system because the brain and the visual system are still developing and demonstrate plasticity (i.e., still flexible, able to be shaped). The concept of plasticity means that the visual system is still growing and maturing in young children. For example, there continues to be an increase in the number of neural cells, maturation of neuronal elements, and the growth of neural networks in the early childhood years. This means that the development of the visual system can still be influenced by the quality and level of visual input received. Proper development of the visual system requires clear images on the back of both eyes. (see Chapter II for additional information.)

Because of the plasticity of the visual system when the child is young and the importance of good vision for the developing visual system, early identification and intervention for young children with vision impairment are especially important. 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.

**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.

# **Recommendations (General Considerations for Medical and Surgical Interventions)**

#### General considerations

- 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. It is also important to remember that a particular child may have more than one reason for vision impairment. [D2]
- 2. It is important to recognize that there is a window of opportunity for influencing the child's visual system because the brain is still developing during infancy and early childhood. The visual system can be influenced more quickly earlier rather than later in life. What may influence the visual system over days in a very young child may take weeks or months in an older child. [D2]
- 3. 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. [D2]

Table 22: Examples of Medical and Surgical Interventions  Conditions That May Result In Low Vision In Young Children			
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		

Table 22: Examples of Medical and Surgical Interventions  Conditions That May Result In Low Vision In Young Children			
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		
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)			

4. It is important to recognize that one of the most important factors for promoting good development of the visual system is to ensure the eye is able to receive clear, well-focused images on the retina. A clear visual image focused on the retina is needed to stimulate development of the visual pathways in the brain. [D2]

- 5. 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. The following are conditions that may obstruct the visual axis:
  - Cataracts
  - Ptosis (drooping eyelid) when it occludes the pupil
  - Corneal opacity
  - Vitreous hemorrhage [D2]
- 6. When making decisions about medical or surgical treatment, factors that influence the visual prognosis (likely clinical course and outcome) include:
  - Age of onset of visual deprivation
  - Duration of visual deprivation
  - The level of visual deprivation (is it partial or total) [D2]
- 7. It is important to understand that in general, the earlier the onset of a vision impairment, the longer the duration of the vision impairment, and the greater the level of visual deprivation, the poorer the response will be to any treatment to improve vision. [D2]
- 8. 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. [D2]

# Craniofacial anomalies

9. It is important that children with craniofacial anomalies have an early comprehensive medical evaluation because they frequently have multiple medical problems. They should also have a comprehensive visual assessment because they frequently have vision problems. [D2]

# Corneal opacities

10. It is important to understand that for children with significant visual obstruction due to corneal opacities, corneal transplants may be an option. However, full thickness corneal transplants (penetrating keratoplasty) are controversial for children who are younger than 3 years of age, particularly when the corneal opacity is unilateral. In general, results of full-thickness corneal transplants in infants tend to be poor. Complications from the corneal transplants are frequent and may result in other problems. [D2]

#### Cataracts

- 11. A thorough evaluation of cataracts in young children is important in order to determine 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
  - Bilaterallity of cataracts
  - Tendency for progression (including family history)
  - Prenatal history
  - Coexisting ocular abnormalities [D2]
- 12. 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)
  - Treatment for amblyopia (may be secondary to cataract) [D2]

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.

#### Glaucoma

- 13. It is important to recognize that early diagnosis of glaucoma in young children may be difficult. [D2]
- 14. Infant glaucoma (unlike adult glacoma) generally requires surgical intervention. It is important to understand that multiple surgeries and frequent examinations under anesthesia may be necessary. [D2]

15. Eye drops may also be used to treat glaucoma in young children. If eye drops for glaucoma are used, it is important for parents to be aware of the systemic effects that may occur in young children. [D2]

*Vitreo-retinal problems/retinopathy of prematurity (ROP)* 

- 16. For infants at high risk for retinopathy of prematurity (ROP), ongoing medical surveillance (both in the neonatal nursery and after discharge) is crucial. Although ROP can usually be diagnosed within the first few months, it is important to continue monitoring the vision of low birth weight premature infants until the retina is fully vascularized (determined by ophthalmoscopy). [D2]
- 17. 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. [D2]

Vitreo-retinal problems/retinitis pigmentosa (RP)

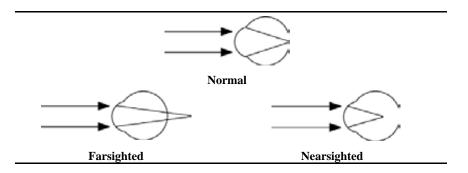
- 18. It is important to recognize that retinitis pigmentosa (RP) is a degenerative retinal condition that causes a decrease in vision. However, functional visual problems from this condition seldom occur in children younger than 10 years old. Currently there is no known effective treatment for this condition. [D2]
- 19. 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 younger than 3 years of age with electrophysiological testing. [D2]
- 20. 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 [D2]
- 21. 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. [D2]

Cortical visual impairment and optic atrophy

22. 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 (e.g., hydrocephalus, which can be treated with a shunt). [D2]

# **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. 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).



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, or when appropriate with intraocular lenses, can usually compensate for abnormalities in any or all of these factors.

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.

## **Recommendations (Optical Correction)**

- 1. It is important to consider the following when determining optical correction for refractive errors in young children:
  - Not all conditions benefit from optical correction
  - It may be difficult to fit young children
  - It may be difficult for young children to comply with wearing glasses [D2]
- 2. It is important to remember that corrective lenses can improve visual problems due to refractive errors, such as nearsightedness or farsightedness, but cannot improve decreased vision due to other problems. Therefore, not all children with vision impairment will benefit from corrective lenses, although corrective lenses can improve visual function for many children with vision impairment. [D2]
- Contact lenses instead of glasses are generally recommended 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. [D2]
- 4. Although intraocular lenses (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 do (Olitsky 1997). [D2]
- It is important to recognize that laser refractive surgery such as LASIK is not approved in the United States for children younger than 18 years of age. [D2]
- 6. It is recommended that selection of specific types of corrective lenses and materials be based on the specific needs of the child. The eye care professional can specify types and/or help advise parents when selecting the most appropriate lenses and materials. [D2]
- 7. When parents/professionals select glasses for children under 3 years of age, it is important that:
  - The lenses and frames of the glasses meet national standards for safety set by the American National Standards Institute
  - The child have frames that are an age-appropriate size
  - The frames are appropriately fitted
  - The fit of the frames is adjusted regularly
  - Tints be used appropriately, particularly with children who have achromatopsia and other conditions with glare sensitivity [D2]

- 8. It is recommended that for children with only one functional eye, protective lenses be worn at all times to protect the eye even if optical correction is not indicated. [D2]
- 9. It is recommended that bifocals be prescribed when accommodation is limited (such as for children with aphakia, i.e., children without a lens following cataract surgery). [D2]
- 10. If bifocals are not well accepted by the child, then it may be more useful to prescribe lenses for children under 3 years old to correct for near vision (as opposed to distant vision) because most of their visual world is up close. [D2]

# INTERVENTIONS FOCUSED ON IMPROVING VISUAL FUNCTION

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental Characteristics study

[D1] = Literature searched but no evidence [D2] = Literature not reviewed

Topics covered in this section:

- General Approach for Improving Visual Function
- Vision Stimulation

Basis for the recommendations in this section

The recommendations for improving visual function for young children with vision impairment include a combination of evidence-based and panel consensus recommendations. Some of the consensus recommendations in this section relate to topics for which a literature search and review to identify evidence were conducted, but no evidence meeting the criteria for this guideline was found. In the panel's opinion, these recommendations reflect appropriate practices for providing interventions to young children with vision impairment and are generally consistent with the scientific knowledge in this field.

## **General Approach for Improving Visual Function**

Visual function refers to how a child uses whatever vision the child has to perceive, respond, interact, and to function within his or her environment. In general, 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 (SKI-HI Institute 1995)

# **Recommendations (General Approaches for Improving Visual Function)**

General considerations for improving visual function

- 1. 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 vision can be enhanced and optimized [D1]
- 2. It is important to encourage the child to use vision in increasingly advanced ways, as well as to find the limits of his/her visual abilities. [D2]
- 3. It is important that any program designed to improve visual function be structured to be consistent with the natural routines of the child's day and be useful in the child's natural environments. [D2]

Environmental modifications to enhance visual function

- 4. Important environmental considerations when interacting with children with vision impairment 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 highcontrast materials and complementary colors
  - Use #4 pencils and broad-tip markers
- Size
  - Determine the object size the child sees 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 when sitting in a chair
  - Encourage some time in prone position (see ♥ Note on page 163) [D2]
- 5. 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 [D2]
- 6. For the child with useable vision, it is important to include activities that promote eye-hand coordination because this is the basis for manipulative play as well as for functional skills such as feeding and dressing. [D1]

# **Vision Stimulation**

As used in this guideline, vision stimulation includes various approaches and techniques to stimulate the child's use of vision by teaching strategies to maximize the child's functional visual responses.

Vision stimulation approaches 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.

Visual functions that are the target of vision stimulation generally include:

- Visual attention/visual awareness
- Fixation
- Shift of fixation (saccades)
- Ocular motilities (eye movements)
- Eye tracking (pursuits)
- Binocularity
- Focusing (accommodation)
- Eye-hand coordination

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

- Acknowledge and respond to the presence of a visual stimulus, such as 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
- 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

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. In general, vision therapy/vision training typically refers to techniques used with older children and adults. Therefore, evaluation of these approaches is outside the scope of this guideline.

## **Recommendations (Vision Stimulation)**

- 1. It is recommended that professionals providing vision stimulation programs involving manipulation of the environment to promote use of vision on various levels have appropriate training and experience.
  - [B] (Behl 1993, Sonksen 1991)
- 2. It is important to consider the aspects of vision stimulation that parents can learn to provide and reinforce in the child's natural environments.

  [B] (Behl 1993, Harley 1987, Leguire 1992)
- It is important to recognize that there was limited evidence from controlled studies to demonstrate the efficacy of vision training/vision therapy for improving functional vision skills in young children with vision impairment.

[C] (Leguire 1992)

Table 23: Examples of Vision Stimulation Activities		
Moderate Low Vision	<b>Profound Low Vision</b>	Near Total Blindness
Visual Attention		
Provide colorful toys, talk to baby face to face	Use black & white toys, use toys that light up and play music	Expose child to light coming through window; use colors and patterns on a lightbox
Tracking		
Encourage play with bubbles, wind toys, balls, and cars	Use flashlights with colored filters	Talk to the child as you slowly walk around the room; have the child run his/her fingers over a raised line as you shine a penlight behind it

### **Table 23: Examples of Vision Stimulation Activities**

#### **Eye-Hand Coordination**

Provide solid color table tops that contrast with fine motor toys; provide a reading stand to use for coloring and stacking Use a desk lamp to focus light on fine motor toys; provide a reading stand to use for coloring and stacking

Provide hand-over-hand prompting and lots of practice for fine motor skills necessary or interesting for the child

(Continued from previous page)

# **ORIENTATION AND MOBILITY TRAINING INTERVENTIONS**

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental Characteristics study

[D1] = Literature searched but no evidence [D2] = Literature not reviewed

This section addresses orientation and mobility training.

The goal of orientation and mobility (O&M) instruction is for visually impaired persons 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

The specific methods and techniques used for O&M instruction are based on the resources, priorities, and concerns of the child and family as determined during the assessment of orientation and mobility (page 93). In general, O&M training activities typically focus on the development of the following (Table 24, page 150):

Formal *orientation* skills:

- 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 or can also be performed with a long cane; can be used for mobility in a familiar area)

## Formal *mobility* skills:

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

# Orientation and mobility (O&M) devices and techniques

Orientation and mobility devices such as canes and techniques such as using a human guide are commonly used by persons with vision impairment to facilitate safe travel. Orientation and mobility devices can range from inexpensive or homemade low-tech devices to very expensive high-tech assistive devices. A variety of effective O&M devices can easily be made by parents or purchased commercially, usually through specialty catalogs. Some O&M devices must be custom designed based on the child's specific needs. There are a limited number of safe techniques that can be used for independent mobility with children younger than 3 years of age.

# Basis for the recommendations in this section

The recommendations for orientation and mobility training for young children with vision impairment are panel consensus recommendations. No studies specific to the topic of orientation and mobility interventions for young children with vision impairment were found that met the criteria for evidence. In the panel's opinion, these recommendations reflect appropriate practices for providing interventions to young children with vision impairment and are generally consistent with the scientific knowledge in this field.

### **Table 24: 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 (increase 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

## **Recommendations (Orientation and Mobility Training)**

## General O&M training considerations

- It is important to understand that mobility is difficult to teach in isolation. It
  is important also for the O&M specialist to consult with other team
  members about the O&M skills to be reinforced and to determine what
  skills would benefit the child. [D2]
- 2. It is important to teach O&M using direct body-to-body contact and mimicry (modeling) or mimicry with assistance. [D1]
- 3. 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. [D1]
- 4. It is important to recognize that in the United States, professionally trained guide dogs are not available to individuals younger than 16 years of age. [D2]

## Developing the O&M plan

- 5. It is important to individualize the O&M plan to the specific needs of the child and family. The frequency of service depends on factors such as the amount of residual vision, the age of the child, the child's history of milestone acquisition, and the need to access safe and independent travel. The anticipated future mode of travel is also a major factor when determining the O&M plan. For example:
  - If it is anticipated that a child will be a visual traveler (i.e., vision will be used as a primary method of orientation and travel with assurance of safety), a monthly consult and parental education may be sufficient
  - If it is anticipated that a child will be a primary visual traveler (i.e., a child who, due to severity of vision impairment or preference, may travel primarily by sighted guide, cane, or adaptive tactile methods), a more intensive program of consultation, parent education, and direct instruction may be needed [D2]
- 6. For most children younger than 3 years of age, it is recommended that O&M skills training be included as a part of the child's total intervention plan. [D1]

#### Selecting O&M devices and techniques

7. When selecting a mobility device or technique, it is important to consider any parental concerns regarding ease of use and transportation, storage, and social acceptability of any recommended travel device [D2]

8. It is important that the professional be sensitive to parental concerns regarding the possibly negative stereotype of a long white cane or premobility device. [D2]

## Considerations for cane use

- It is important to recognize that precane devices include both commercially available toys and homemade devices. Although there are many articles in specialty journals that describe homemade precane devices, many O&M specialists recommend commercially available push toys as precane devices. [D2]
- 10. It is recommended that a cane, if needed, be introduced when the child moves from cruising to independent walking. [D1]
- 11. 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 cane tip is chosen to facilitate specific cane or travel techniques. [D2]
- 12. It is important for initial cane instruction to emphasize constant contact (the cane tip should be on the ground at all times) and diagonal techniques (the cane held forward and slightly across the body). [D1]

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.

### O&M training for children who use wheelchairs

- 13. It is important to recognize that the coordination required for wheelchair use is not well developed generally in children under the age of 3 years. [D1]
- 14. For young children with vision impairment who use a wheel chair as their primary mobility device, it is recommended that training emphasize detection of obstacles and changes in the terrain. For example:
  - For children with residual vision, a clear tray may be recommended so they can see past their feet to the ground
  - Bumpers made out of hula-hoops or similar flexible material, or curb feelers available in auto accessory stores, can assist in the detection of obstacles and trailing of parallel surfaces [D2]

Parent education as a component of O&M training

- 15. 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. [D2]
- 16. It is important for parent education regarding mobility devices (both precane and long cane) to emphasize consistent and safe use as recommended. [D2]
- 17. It is important that O&M instruction include working with the parents to find ways within the child's natural environment to encourage and ensure safe travel, including the usual kind of childproofing, as well as use of high contrast, texture, or lighting to delineate areas of concern. It is important also to make the natural environment attractive to the child and encourage the child's movement and exploration by placement of toys or moving the furniture if needed. [D2]

#### INTERVENTIONS FOR SPECIFIC DEVELOPMENTAL DOMAINS

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental Characteristics study

[D1] = Literature searched but no evidence [D2] = Literature not reviewed

Topics covered in this section:

- General Approach to Developmental Interventions
- Cognitive Development
- Sensory and Motor Development
- Communication Development
- Adaptive/Self-Help Skills
- Social/Emotional Development

Basis for the recommendations in this section

The recommendations about developmental interventions for young children with vision impairment are primarily panel consensus recommendations. For

some topics, the literature was searched, but no evidence meeting the criteria was found. In the panel's opinion, these recommendations reflect appropriate practices for children with vision impairment and are generally consistent with the scientific knowledge in this field.

# **General Approach to 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). Much of children's basic early learning is achieved through observation and imitation. The learning that occurs through observation and imitation begins in the first months of life and affects all developmental domains. Developmental learning also occurs through exploration of children'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).

### **Recommendations (General Approach to Developmental Interventions)**

General considerations for developmental interventions

- It is recommended that desired outcomes for the child be clearly identified and defined with developmentally appropriate measurable criteria for mastery. [D2]
- 2. 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 use of the other senses. [D2]
- 3. It is important that interventions to foster the child's development:
  - Help parents gain a broader understanding of their child's cognitive and sensorimotor development
  - Facilitate parent-child interactions
  - Include objectives that can be achieved by incorporating activities into the daily routines of the child and parent
     [B] (Behl 1993, Harley 1987)

- 4. Important considerations when implementing developmental interventions include:
  - Avoiding clutter
     (too many toys may make it more difficult for the child to focus, and easy access to one or two toys promotes more detailed exploration of each item)
  - Minimizing distracting noises
  - Being aware of lighting:
    - Illuminate persons or objects that are the focus of the child's attention
    - Avoid glare
  - Talking to the child to help the child conceptualize the environment and to increase the child's awareness of other senses (touch, taste, smell) [D2]
- 5. Most young children with vision impairment can benefit from experiences in an environment with clear boundaries (e.g., an appropriate enclosed play space). It is important to provide these experiences to help the child develop a sense of self in relation to the environment. [D2]
- 6. It is important to include opportunities for exploration within a safe environment (e.g., a play space with clear boundaries) that will facilitate learning through other senses, particularly touch, hearing, and movement (textured mats and toys, toys with auditory components, etc.). [D2]
- 7. 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. [D1]
- 8. 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 who have hearing, it is important to provide auditory cues, such as explaining what is happening, before touching them. [D2]
- 9. For children with severe vision impairments and other disabilities in addition to vision impairment, it is important to use strategies that include coactive movement. *Coactive movement* refers to the teacher performing tasks with the child seated on the teacher's lap. Maximum body-to-body contact is 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, which is then further reduced to verbal or simple touch cues. [D2]

## **Cognitive Development**

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 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 (SKI-HI Institute 1995)

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 to make certain associations and develop concepts using tactual and auditory information. For example, a doll might look like a baby, but it does not feel nor sound like one.

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

#### **Recommendations (Cognitive Intervention)**

General considerations for cognitive interventions

 It is recommended that interventions to enhance cognitive development in young children with vision impairment include a multimodal, multimethod approach including:

- Multiple settings, as appropriate, such as the home, community, childcare settings, and typical social environments
- Multiple modalities such as using objects of various sizes, shapes, and textures; sounds, experiences of motion and movement; etc.
- Multiple interventionists [D2]
- 2. It is important to include the following in cognitive interventions:
  - Activities to promote information processing skills such as cause-andeffect activities
  - Both short-term and long-term memory activities such as repetitive games, songs, and rhymes
  - Motivating tasks and reinforcement contingencies specific to the child [D2]
- 3. It is important to provide information to parents that will help them:
  - Identify opportunities to enhance cognitive skills in everyday activities
  - Promote opportunities for generalization of developmental skills [D2]
- 4. It is important that the objectives of interventions for cognitive development be related to enabling the child to function as independently as possible within the child's environment. [D2]

#### Cognitive intervention approaches

- 5. 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 25, 26, 27, and 28; pages 158-159) and about approaches that may help stimulate cognitive development. [D2]
- 6. Well-designed toys with highly reactive features can be especially useful for promoting cognitive development in young children (Table 27, page 159). [D1]
- 7. It is recommended that children 12 to 24 months old begin to be introduced to group learning experiences. This is important because children of this age begin to be able to model or imitate other children and adults. [D2]
- 8. It is important to provide exposure to new experiences and to allow the child to develop a natural interest in different activities (in other words, provide opportunities but do not force the interest). [D2]
- 9. When introducing new activities to the child, it is important to use hand-under-hand or hand-over-hand guidance to show the child how to play with the toys or use new materials, and to accompany this manual guidance with descriptive language that relates the play to the child's own experiences. [D2]

# Table 25: 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 26: Considerations for Promoting Exploration of the Environment for Young Children With Vision Impairment

- 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, such as a playpen, tray, or placemat, with tactile boundaries and some fixed objects for safe exploration
- Positioning furniture to promote mobility (crawling, walking, etc.)

# Table 27: Important Characteristics of Play Items for Young Children With Vision Impairment

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

# Table 28: Age-Specific Approaches: Cognitive Interventions

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

#### 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

## Table 28: Age-Specific Approaches: Cognitive Interventions

#### 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 in the crib that moves when the child moves

#### 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, baby dolls, etc.) 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 away groceries, 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)

- 10. It is important to include opportunities for interaction with other children in structured and semistructured activities. Exposure to chronologic and/or developmental-age peers will help to facilitate the attainment and reinforcement of cognitive skills. [D2]
- 11. It is important to provide opportunities for generalization and exploration that enable children to develop mastery and competencies within their environment. [D2]
- 12. It is important to be aware of and cautious about toy safety as children develop more independent motor skills (e.g., rolling, reaching, mouthing and manipulating objects, mobility skills). In particular, parents should be aware of:

- Small objects (including removable items on toys or other objects) that could be swallowed or which the child might choke on
- Strings on toys (or other objects such as window blinds) that could wrap around body parts
- Sharp objects that could cut or puncture [D2]

#### **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. Because the surrounding environment cannot be clearly observed, children with vision impairment tend to be less motivated to reach for and move toward objects. This lack of motivation can lead to reduced activity and can affect both gross and fine motor development (SKI-HI Institute 1995). Vision impairment also reduces the child's ability to observe and imitate the movements of others.

The degree to which the vision impairment affects a child's motor development depends on many 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 with gross motor development in young children with vision impairment include:

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

The most common problems with fine motor development in young children with vision impairment 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

Development of the child's sensory systems (the ability to take in information through sight, hearing, touch, smell, taste, and movement, and process the information in order to respond to it) may also be affected by the vision impairment (Huebner 1995). Children with vision impairment may show tactile defensiveness (such as an adverse response to certain textures or temperatures

and/or reluctance to touch anything placed in the hands) and/or gravitational insecurity (Johnson-Martin 1991). In some children, other sensory systems (hearing, touch, smell) may be hypersensitive, but in other children they may be underdeveloped.

## **Recommendations (Sensory and Motor Intervention)**

General considerations for sensorimotor interventions

- 1. 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 [D1]
- 2. As the child progresses through the motor milestones, it is important that there be a safe and familiar environment in which the child can practice his/her developing skills. It is important also to provide the child with opportunities that will encourage the use of sensorimotor skills and promote generalization of skills to new environments (Table 29, page 163). [D1]
- 3. It is important to recognize and understand that young children with significant vision impairment need to develop the confidence that they will be safe during activities. [D2]

## Gross motor development

- 4. It is important for infants to be positioned correctly and spend time in different positions (back, stomach, side-lying, and sitting) to promote good neuromuscular and musculoskeletal development. [D1]
- 5. It is important to provide children with vision impairment the opportunities and experiences to promote development of gross motor skills. [D1]
- 6. Basic principles of providing motor interventions for young children with vision impairment include:
  - Using proper positioning to support low muscle tone
  - Using safe, age-appropriate, multisensory, materials
  - Using manual guidance to help the child move through different positions
  - Keeping the environment consistent as the child is learning new motor skills (e.g., do not rearrange the furniture) [D1]

# Fine motor development

- 7. It is important to facilitate fine motor development during the child's natural daily routines such as feeding, bathing, dressing, and playing. [D1]
- 8. Activities that can help promote development of fine motor skills include:
  - Touching, reaching for, grasping, and releasing objects
  - Banging hands and objects on a variety of surfaces
  - Bilateral (both hands) manipulation of objects (twisting, turning, exploring)
  - Putting objects in/taking objects out of containers to help develop spatial concepts [D1]

## Table 29: Age-Specific Approaches: Sensory and Motor Interventions

The following are examples of sensory and motor intervention approaches that may help stimulate cognitive 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 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. For example:
  - 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 progressing to sitting independently, provide lots of simple movement activities such as:
  - Bouncing the baby on the knee
  - Gently pulling a blanket across the floor with the baby in a prone position

#### Table 29: Age-Specific Approaches: Sensory and Motor Interventions

#### 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 farther 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 age-appropriate playground and art skills:
  - Slides, swings, jungle gyms, tricycles, and balance beams
  - Finger painting with a variety of textures and smells
  - · Hide-and-seek games
  - Throw, catch, and kick balls with bells inside
  - Paste objects of different shapes and textures

(Continued from previous page)

## Sensory development

- 9. It is important to remember that a young child with vision impairment obtains information about the environment with an increased dependence on other senses. Promoting the child's awareness of and response to sensory stimuli can be encouraged by providing opportunities to experience such as:
  - Different sounds associated with different objects or experiences
  - Different smells that might be enjoyable
  - Objects that have a variety of textures
  - Exploration of safe objects by mouthing [D1]
- 10. It is important for the child to develop body awareness through whole body activities such as swaddling, swinging, rolling, bouncing, and rocking. [D1]
- Providing a child with sufficient sensorimotor activities may reduce or prevent development of stereotypical behaviors such as repetitive mouthing, repetitive hand motions, eye-poking, and/or nonfunctional use of toys. [D1]

## **Communication Development Intervention**

Much of communication is nonverbal and involves the sense of 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 (Burlingham 1974, Fraiberg 1977). Communication with these infants 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 in fact it indicates 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:

- Imitation and reciprocity are initially learned from visual cues
- Visually impaired children tend to have lags in object concept
- Reduced eye contact has an effect on attachment and socialization
- Development of appropriate conversation depends on developing concepts of self versus other, and vision plays a role in developing concept of self/other

The impact of vision impairment on communication development may include:

- Reduced ability to initiate interactions with others
- Reduced ability to 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 pragmatics (turn-taking and conversational rules)
- A tendency toward verbalism (long strings of grammatically correct phrases that have little to do with what is going on or what others are talking about) (Ferrell, 1986)

#### **Recommendations (Communication Intervention)**

It is important to understand that many children with vision impairment
may also have delays in speech and language development. In general, the
degree of communication delay tends to correlate with the severity of the
vision impairment (communication tends to be more delayed in children
who are blind or have severe vision impairment).

[Bdc] (Hatton 1997)

- 2. It is important to talk to young children with vision impairment to help facilitate the development of early communication. [D1]
- 3. When speaking to young children with vision impairment, it is important to help the child develop communication skills and a meaningful language environment. It is particularly important to:
  - Use age-appropriate language
  - Speak clearly and repeat or reword when necessary
  - Use natural language, including words with visual reference such as "look," "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 and include 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 the child's developmental age and ability [D1]
- 4. It is important to understand that language can be a substitute for vision in conceptualizing the environment. Therefore, it is important to describe verbally objects and actions. Tactile experiences should be described to enrich language and link words to objects. [D1]
- 5. It is important to understand how the tone and expression of language conveys emotion and other messages. Because children with vision impairment are not able to see visual cues such as facial expression, it is important to assist them to experience both your and their own facial expressions tactilely. [D1]

- 6. It is important to adjust the listening environment by reducing or eliminating auditory distractions such as nonspecific background noise (TV, radio). This will help the child focus on and differentiate specific auditory inputs and other aspects of the environment. [D1]
- 7. It may be helpful to use communication devices, such as recordable message devices and communication boards modified for low vision, for young children with vision impairment who also have communication problems (see "Assistive Technology," page 174). [D1]
- 8. It is important to recognize that all children can benefit from preliteracy/emerging literacy activities. These may include adapting/providing books and materials in large print, or 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) [D2]

## **Table 30: Age-Specific Approaches: Communication Interventions**

The following are examples of intervention approaches that may help stimulate communication development of children with vision impairment:

#### 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 its mouth to explore safe objects

#### Age 3 to 6 months

- Imitate consonant and vowel sounds
- Play tickling and bouncing games to elicit smiles and giggles
- Begin to prompt and reinforce when the child turns toward sound and speech
- Encourage the child to explore your face tactilely when you are speaking

## Age 6 to 12 months

Encourage the child to imitate simple sounds

## **Table 30: Age-Specific Approaches: Communication Interventions**

#### 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 the 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

#### Age 24 to 36 months

- Encourage child to follow two-step directions
- Ask "Where" questions
- Ask "What are you doing" questions
- Encourage correct use of pronouns
- Encourage use of three-word phrases

(Continued from previous page)

# Adaptive/Self-Help Skills Intervention

Adaptive/self-help skills refer to the way children learn to take care of themselves. These skills include sleeping, feeding, dressing, toileting, grooming, and caring for belongings. Because of sensorimotor difficulties such as tactile defensiveness, young children with vision impairment/blindness may have difficulty eating and/or feeding themselves.

Studies (Troester 1996, Mindell 1997) indicate that young children with vision impairment/blindness demonstrate more sleep problems than do sighted children and that the degree of the problem is dependent on the severity of the vision impairment.

## **Recommendations (Adaptive/Self-Help Skills)**

General approach to adaptive/self-help interventions

- 1. 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 [D1]
- 2. It is important to recognize that teaching adaptive/self-help skills, especially the exploratory/investigative phase, to a young child with vision impairment may be time-consuming and initially result in frustration on the part of both the child and the adult. [D2]
- 3. It is important to understand that developmentally, a child first learns a specific skill, then incorporates the skill into a daily routine, and finally uses the skill appropriately and independently as needed. It is important to introduce adaptive techniques for self-care when it is developmentally age-appropriate for the child and in a natural setting. For example, eating skills are best worked on during mealtime. [D2]

## Feeding skills – infants

- 4. 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 trust the feeder. [D2]
- 5. 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 in general, it is important for the infant to be in charge of the initiation, pace, and timing of the feeding. [D2]
- 6. 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. [D1]
- 7. It is important to recognize that an infant with vision impairment may be at risk for oral and tactile sensitivity. For some children, patience and consistency may help reduce or eliminate the oral hypersensitivity. [D1]

## Feeding skills – older children

- 8. It is important for children with vision impairment to participate in the mealtime process as a member of the family. [D2]
- 9. 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. [D2]
- 10. It is 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. [D2]

# Addressing sleeping problems

11. If a child with vision impairment is having a problem sleeping, it is important to consider whether any treatable medical problems are 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. It is important to consult the child's physician for help with potential medical causes of sleep disturbance. [D2]

# **Table 31: Techniques for Developing Mealtime and Eating Skills**

- Establish routines
- Talk about the food; let the child know food is coming
- Let the child help as much as possible
- Let the child control the pace
- Wait for the child's mouth to open
- 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
- 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 32: Techniques for Developing Sleep Patterns**

- Establish consistent waking times and daytime routines such as regular times for meals, activities, and naps
- Develop bedtime rituals
- Make reasonable adjustments to the child's nap schedule and bedtime to accommodate natural sleep-wake cycles
- Set limits (and be consistent) on attention-getting behaviors and availability of interesting toys at bedtime
- Provide an environment such as 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 activities in the bedroom to diaper changing and dressing, etc.
- Avoid drinks that contain caffeine and discourage excessive evening fluids
- Avoid medications to help the child sleep

# **Social/Emotional Development Intervention**

Social development refers to how children learn to interact with parents, siblings, friends, teachers, playmates, etc. Emotional development refers to how children learn to feel about themselves and others, and how they develop feelings of competency. Vision 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 or participate in group activities
- Increased tendency for self-stimulation behaviors, such as eye-poking

#### **Recommendations (Social/Emotional Development Intervention)**

General considerations for social/emotional development interventions

1. It is important for parents, professionals, and others to learn how to approach the child in a way that does not startle or frighten. To avoid frightening a child, it is important to:

- Use an auditory cue first and tell the child what you are going to do before picking up or touching the child for activities or care
- Introduce yourself by name to help the child recognize the voice when beginning an interaction or activity with the child [D1]
- It is important to recognize that imaginative play can be difficult for young children with vision impairment. It is important to encourage pretend play by involving the child as much as possible in everyday activities such as preparing meals, cleaning, talking on the phone, or going with the parent on errands. [D2]
- 3. 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 a sighted child does. Very young children with vision impairment generally tend to need close proximity when using their sense of touch, smell, and hearing to identify different people. [D2]
- 4. In order to facilitate attachment and to assist the parent in laying the foundation for the child's social development and self-esteem, 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 seem. [D1]
- 5. Because early attachment is critical for future social development and selfesteem, it is important that parents of children with vision impairment understand that an infant with 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
  - Social smiling develops later in infants with significant vision impairment
  - It may be difficult to interpret the needs of infants with significant vision impairment because they may be more passive and may not seek attention by crying [D1]
- 6. 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 play dates. The child can be taught to play catch using a ball with a bell inside, introduced to a toy kitchen, shown how to play with dolls, and taught finger play songs through hand-over-hand or hand-under-hand prompting. [D1]

- 7. 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 because it may be more difficult to discriminate the auditory information. This may be especially difficult for children who have low contrast sensitivity and have difficulty seeing expressions or recognizing faces. [D1]
- 8. It is important to provide activities and opportunities for sensory motor movement and exploration to discourage self-stimulatory behaviors. [D1]

# Table 33: Age-Specific Approaches: Social/Emotional Interventions

The following are examples of intervention approaches that may help to stimulate social/emotional development:

#### **Birth-6 months**

- Keep the baby close and talk to, touch, and hold the baby as much as possible; the child will learn to know the parent through 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 (e.g., keep favorite toys, clothes, and snacks in areas that are accessible)

# **ASSISTIVE TECHNOLOGY (AT)**

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental Characteristics study

[D1] = Literature searched but no evidence [D2] = Literature not reviewed

This section addresses the general approach for the use of various assistive technology devices for young children with vision impairment. Assistive technology devices include low vision aids, mobility aids, access aids, play/learning materials, and other devices to assist with the activities of daily living.

A variety of assistive technology (AT) devices can help young children with vision impairment perform many daily life activities (Table 34, page 175). The goal of AT should be for the child to be able to function at a higher level of efficiency with the device than without it. The appropriateness of any assistive technology device depends on the developmental age and specific needs of the child and family. Some devices may be useful for older children but may not be as useful for younger children. Families need to be informed about the range of available AT options. In general, low-tech devices are usually simple, easy to use, and low cost, while high-tech devices typically are more complex and require specialized training to use.

## 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."

Assistive technology support includes purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices; selecting,

designing, customizing, fitting, adapting, 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 a child.

Basis for the recommendations in this section

The recommendations for assistive technology for young children with vision impairment are primarily panel consensus recommendations. A literature search to identify evidence was conducted, but no evidence meeting the criteria for this guideline was found. In the panel's opinion, these recommendations reflect appropriate practices for providing interventions to young children with vision impairment and are generally consistent with the scientific knowledge in this field.

Table 34: Examples of Assistive Devices for Young Children With Vision Impairment

Impairment		
AT Category	Examples	
Vision Aids	<ul><li>Eyeglasses</li><li>External contact lenses</li><li>Magnifiers</li></ul>	
Positioning Devices	<ul> <li>Wedges, rolls</li> <li>Seat inserts</li> <li>Adapted seating systems</li> <li>Adapted potty chairs</li> </ul>	
Premobility and Mobility Devices	<ul><li>Adapted push toys, canes</li><li>Walkers</li><li>Scooter boards</li></ul>	
Play/Learning Aids	<ul> <li>Reactive play items with music, sound, vibratory feedback</li> <li>Switches, adapted switch toys</li> <li>Items with differentiated access areas</li> <li>Adapted computer peripherals (switch interface, adapted keyboards)</li> <li>Tactile books, puzzles</li> </ul>	

<b>Table 34:</b>	<b>Examples of Assistive Devices for Young Children With Vision</b>
	Impairment

AT Category	Examples	
Access Materials	<ul> <li>Attachments that bring items closer to the child (plastic links)</li> </ul>	
	<ul> <li>Extenders that help children locate and access toy features (page turner)</li> </ul>	
	<ul> <li>Stabilizers or confinement materials that prevent a toy from moving out of the child's reach</li> </ul>	
	<ul> <li>Highlighters placed on surfaces to make things easier to find (fluorescent tape, locator dots, various textures)</li> </ul>	
Communication Devices	<ul> <li>Communication boards with adapted labels (textures, contrast, line drawings)</li> </ul>	
	<ul> <li>Single, sequential, and multiple recordable message devices</li> </ul>	
(Continued from previous page)		

## **Recommendations (Assistive Technology)**

General approach for assistive technology

1. It is recommended that the need for assistive technology be considered for all young children with vision impairment and that this need be reassessed on an ongoing basis. [D2]



**Early Intervention Policy** The intensity, frequency, and duration of El 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.

2. Assistive technology devices and services are recommended when the use of a device is recognized as having potential benefit for the child and family. Potential benefits may include:

- Improved self-esteem and self-identity, and feeling of control over the environment
- Increased independence and decreased potential for learned helplessness
- Facilitating exploration of objects and people in the environment
- Increased ability to actively participate in interactions with peers [D1]
- 3. It is important that assistive technology have purpose and meaning for both the child and the parent. It must be practical and feasible for the family to use. Assistive technology provides no benefits if it is not used. [D2]
- 4. It is essential that the professionals recommending assistive technology:
  - Be knowledgeable about assistive technology in general, as well as the particular device being recommended
  - Be knowledgeable about the child's disability
  - Consult with the child's other service providers and family
  - Understand (and ensure the 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
  - Ensure that all family members and service providers understand specifically how and when the technology is to be used
  - Provide training and customization to support the use of the device [D2]
- 5. When educating families about assistive technology, it is important to:
  - Help them make the best decision for their child
  - Ensure they know how to use the device
  - Ensure the family understands how to properly maintain and care for the device [D2]
- 6. It is important to monitor the use of the assistive technology device and services to ensure that it is:
  - Meeting the needs of the child and family
  - Changed if the child's needs change [D2]

7. It is important to understand that recommending an assistive 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 but often provides an opportunity to learn new skills. [D1]

# General approach for selecting AT devices

- 8. It is important that the child's vision professional be consulted, and that the need for and appropriateness of any assistive technology for a child with vision impairment be based on the child's current needs. [D2]
- 9. It is important to recognize that low-tech devices can be as effective as high-tech devices are, but without the complexity and appropriate 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. [D1]
- 10. It is important to recognize that many commercial products have not been scientifically tested for use by young children with vision impairment. Some AT devices are more appropriate for older children or children at a higher developmental level. Parents and professionals need to ensure that the AT device is appropriate and safe for that child. Examples of AT devices generally not appropriate for young children with vision impairment 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 [D1]
- 11. It is recommended that when possible, the child and family be given an opportunity to try the device during a trial period. [D2]
- 12. When an AT device has been selected, it is important that appropriate training be provided for persons involved with the child, and that this training be conducted by professionals with appropriate expertise in the use of the device. [D2]

#### ALTERNATIVE INTERVENTION APPROACHES

**Evidence Ratings:** 

[A] = Strong [B] = Moderate [C] = Limited

[dc] = Developmental characteristics study

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

The alternative intervention approaches reviewed in this section include:

- Hyperbaric Oxygen Therapy
- Light Therapy
- Transplants and Implants
- Gene Therapy
- Nutritional and Dietary Supplements

Review of the evidence for the topics in this section

A literature search to identify evidence for the alternative interventions reviewed in this section was conducted, but no evidence meeting the criteria for this guideline was found. In the absence of evidence and because these are not considered standard interventions for young children with vision impairment, the panel chose to make only limited recommendations for these topics.

#### Hyperbaric oxygen

Hyperbaric oxygen therapy (HBOT) uses a pressure chamber to increase the amount of oxygen received by an individual by physically dissolving extra oxygen into the blood plasma. The breathing of pure oxygen at three times normal atmospheric pressure (3 A.T.A.) delivers 15 times as much physically dissolved oxygen to tissues as breathing room air does. HBOT use has been reported for the treatment of a variety of conditions, including treating 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 (or phototherapy) is described as the application of selected visible light frequencies through the eyes. It has also been described as a means of balancing energy flow within the body. It 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

In broad terms, gene therapy generally refers to the attempt to target treatment for a specific condition on the gene or genes responsible for the disorder. Gene therapy approaches are currently undergoing clinical trials directed primarily toward inherited metabolic diseases. These disorders result from the loss of activity of critical enzymes in vital biochemical pathways. The disruption of such a pathway can lead to the excessive accumulation of toxic substances, which in some conditions can harm the visual pathway. For example, excessive build-up in the body of a simple sugar called galactose, from a common disorder of sugar metabolism called galactosemia, can result in congenital cataracts. Another example is the vision impairment caused by an enzymatic block of pigment (melanin) synthesis resulting in loss of pigment of the retina and iris in persons with albinism. Gene therapy holds promise for the future but has not yet resulted in a new available treatment 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.

# **Recommendations (Alternative Intervention Approaches)**

- Because there is no current scientific evidence to support their use for improving vision, it is recommended that the following not be used as interventions for young children with vision impairment: hyperbaric oxygen treatment, light therapy, gene therapy, transplants and implants, and nutritional and dietary supplements. [D1]
- 2. When deciding whether to use a particular approach with a young child with vision impairment, it is important that parents consider information about the intervention's efficacy as well as information about its potential physical risks and any other risks. [D2]

APPENDIX A: METHODOLOGY TABLES

# APPENDIX A

ist of Methodology Tables	
Fable A-1: General Criteria for Selecting Evidence Studies1	85
Fable A-2: Criteria for Adequate Evidence: Assessment Studies1	86
Fable A-3: Interpreting Sensitivity and Specificity1	87
Fable A-4: Criteria for Adequate Evidence: Intervention Methods1	89
Fable A-5: Criteria for Adequate Evidence: Studies Providing Information About  Developmental Characteristics1	90
Fable A-6: Strength of Evidence Ratings for Guideline Recommendations1	91

# Table A-1: General Criteria for Selecting Evidence Studies

For a study to be selected as meeting the criteria for evidence review, a scientific article had to meet all of the general criteria given below, as well as the additional criteria applicable to studies of assessment (Table A-2), intervention (Table A-4), or developmental characteristics (Table A-5).

To meet the general criteria for evidence review, studies had to:

- Be published in English in a peer-reviewed scientific/academic publication
- Use original quantitative data for outcomes of interest and appropriate statistical analysis of results (or be a systematic synthesis of such data from other studies)
- Include data on the child (not just parent reaction or behavior)
- Evaluate children of the appropriate age (meeting at least one of the following criteria):
  - The majority of subjects are ≤48 months of age, or
  - The study group is described as "infant," "toddler," and "early intervention" (EI)

# Table A-2: Criteria for Adequate Evidence: Assessment Studies

Articles meeting the following quality and applicability criteria were considered to meet the adequate evidence criteria for evidence of efficacy of assessment methods for young children with vision impairment. Assessment studies had to:

- A. Meet all the general criteria for evidence in Table A-1, and
- B. Meet the following additional criteria for studies of identification and assessment methods:
  - Evaluate a method currently available to providers in the U.S. (obsolete or clearly
    experimental methods were generally excluded)
  - · Provide an adequate description of the method evaluated
  - Give the sensitivity and specificity of the test or method compared to an adequate reference standard or provide enough data so that these could be calculated
  - Include at least 10 subjects with the condition and at least 10 subjects without the condition (according to the reference standard)

Studies were considered to have high quality/applicability if:

- All subjects are ≤48 months of age or the mean age of the subjects is ≤36 months or all subjects are described as infant, toddler, or EI
- Study design, study population, and results are adequately described and no significant issues are noted regarding factors that might bias results

Studies were considered to have intermediate quality/applicability if:

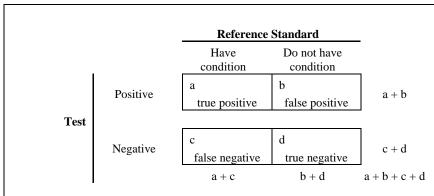
- Age range of subjects is >48 months of age or the mean age of the subjects is >36 months or not reported
- Study design, study population, and results are not adequately described or issues are noted regarding factors that might bias results

# Table A-3: Interpreting Sensitivity and Specificity

The established method for evaluating the efficacy (or accuracy) of an identification or assessment test (or method) is to determine its **sensitivity** and **specificity** compared to an adequate reference standard. These concepts are defined as follows:

- The sensitivity of a test is the percentage of all persons with the condition (according to the reference standard) who are correctly identified by the test as having the condition. Sensitivity is also known as the true positive rate.
- The **specificity** of a test is the percentage of all persons who do not have the condition (according to the reference standard) who are correctly identified by the test as being free of the condition. Specificity is also known as the true negative rate.
- A reference standard is an independent measure to determine if a subject actually has the condition that the test is attempting to identify. It is presumed that the reference standard is a more accurate way to identify the condition than is the test being evaluated. To be useful in calculating sensitivity and specificity, a reference standard must have specified criteria to determine if a person does or does not have the condition.
- Cutoff criteria are the rules to determine if the test or reference standard is positive (indicating the individual has the condition) or negative (indicating that the person does not have the condition).

Term	Definition	Formula
Sensitivity	The percentage of those who have the condition having positive tests	[a/(a+c)] [x100]
Specificity	The percentage of those who do not have the condition having negative tests	[d/(b+d)] [x100]



# Table A-3: Interpreting Sensitivity and Specificity

#### Considerations for interpreting sensitivity and specificity

1. The higher the sensitivity and specificity, the greater the accuracy of the test.

Sensitivity and specificity are expressed as percentages. The perfect test would have both sensitivity and specificity of 100%.

- A test with 100% sensitivity would correctly identify all those with the condition (100% sensitivity = no false negatives).
- A test with 100% specificity would not incorrectly identify a person as having the condition if they did not have it (100% specificity = no false positives).

As sensitivity or specificity decreases, the rate of false negatives or false positives increases. For example,

- A test with 70% sensitivity would correctly identify 7 out of 10 with the condition, and there would be 3 individuals with the condition who are not identified by the test (false negatives).
- A test with 70% specificity would correctly identify 7 out of 10 who do not have the condition, and there would be 3 individuals incorrectly identified as having the condition (false positives).
- 2. What is "acceptable" for sensitivity or specificity depends on the situation.

In the real world, assessment methods for screening and early identification of a disorder rarely have 100% sensitivity and specificity. There is no general agreement about what the acceptable levels of sensitivity and specificity for an assessment test are. Acceptable levels may vary depending upon a variety of factors:

- The intent of the test
- The potential impact of false positives or false negatives
- The setting of testing (general population or a specific subgroup at risk for the condition)
- The prevalence of the condition in the group being tested
- · Alternate methods of assessment
- Costs and benefits of testing
- 3. Changing cutoff criteria affects sensitivity/specificity.

In calculating sensitivity and specificity, the reference standard must use specific criteria to determine if a person does or does not have a condition, and the test must use specific criteria to determine if the test result is positive or negative. Using different cutoff criteria for either the test or the reference standard will yield different sensitivity and specificity. In general, as one goes up, the other goes down.

(Continued from previous page)

#### Table A-4: Criteria for Adequate Evidence: Intervention Methods

Articles meeting the following quality and applicability criteria were considered adequate evidence for efficacy of intervention methods for young children with vision impairment.

For all studies of intervention methods, studies had to:

- A. Meet all the general criteria for evidence in Table A-1, and
- B. Meet the following additional criteria for studies of intervention methods:
  - All subjects have vision impairments
  - Evaluate an intervention method currently available to providers in the U.S. (obsolete or clearly experimental methods were generally excluded)
  - · Provide an adequate description of the intervention method evaluated
  - Evaluate the efficacy of the intervention using functional outcomes important for the child

#### **Group Studies**

- Provide adequate quantitative description of study findings and appropriate statistical analysis of results
- Include a comparison group (receiving an alternate intervention) or a control group (receiving no intervention)
- Report baseline developmental characteristics of subjects

Studies were considered to have high quality/applicability if:

- Subjects are reported to be allocated to groups randomly or using some other method not likely to introduce bias into the study
- Outcomes are reported for at least 10 subjects per group
- All subjects are <48 months of age or the mean age of the subjects is <36 months or all subjects are described as infant, toddler, or EI

Studies were considered to have intermediate quality/applicability if:

- Assembly of study groups is retrospective or the method of group assignment is not specified (but baseline characteristics are generally comparable between groups)
- Outcomes are reported for at least 8 subjects per group
- Age range of subjects is >48 months of age or the mean age of the subjects is >36 months or not reported

Single Subject Design Studies (considered intermediate quality/ applicability)

- Single subject design studies were considered acceptable if they:
  - Use an acceptable single subject design methodology (either multiple baseline or ABAB design), and
  - Include at least 3 subjects with vision impairments who are ≤48 months of age

# Table A-5: Criteria for Adequate Evidence: Studies Providing Information About Developmental Characteristics

Articles meeting the following quality and applicability criteria were considered to meet the criteria for adequate evidence for studies about developmental characteristics of young children with visual impairment. Studies had to:

- A. Meet all the general criteria for evidence in Table A-1, and
- B. Meet the following additional criteria for studies of developmental characteristics:
  - Compare (and adequately describe) characteristics of children with visual impairment with a comparison group of normally sighted children (or compare children with different levels of visual function)
  - Report characteristics for at least 10 children per group
  - Present the same types of data and use similar assessment methods for each group
    of interest

Studies were considered to have high quality/applicability if:

- All subjects are ≤48 months of age or the mean age of the subjects is ≤36 months or all subjects are described as infant, toddler, or EI
- Study design, study population, and results are adequately described and no significant issues are noted regarding factors which might bias results

Studies were considered to have intermediate quality/applicability if:

- Age range of subjects is >48 months of age or the mean age of the subjects is >36 months or not reported
- Study design, study population, and results are not adequately described or issues are noted regarding factors which might bias results

There is a notable difference in the type of scientific evidence obtained from studies about the developmental characteristics of young children who are visually impaired compared with evidence from studies evaluating the efficacy of an intervention or assessment method. Studies about developmental characteristics provide descriptive evidence about the children being studied, while studies about intervention and assessment methods provide evidence about efficacy of the particular method (whether the method works as intended or how well one method works compared with another).

#### Table A-6: Strength of Evidence Ratings for Guideline Recommendations

Each of the guideline recommendations in Chapters III and IV is followed by one of the four "strength of evidence" ratings described below. These strength of evidence ratings indicate the amount, general quality, and clinical applicability (to the guideline topic) of scientific evidence used as the basis for each guideline recommendation.

- [A] = Strong evidence is defined as evidence from two or more studies that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, with the evidence consistently and strongly supporting the recommendation.
- [B] = Moderate evidence is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, and where the evidence supports the recommendation.
- [C] = Limited evidence is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had moderate quality or applicability to the topic, and where the evidence supports the recommendation.
- [D] = **Panel consensus opinion** (either [D1] or [D2]):
  - [D1] = Panel consensus opinion based on information not meeting criteria for adequate evidence about efficacy, on topics for which a systematic review of the literature was conducted
  - [D2] = Panel consensus opinion on topics for which a systematic literature review was not conducted

# Evidence ratings for studies about the developmental characteristics of young children with vision impairment

Recommendations based on information from studies about the developmental characteristics of young children with vision impairment are given Evidence Ratings using the criteria described above, but are noted with a subscript [ $_{dc}$ ] following the Evidence Rating to distinguish them from the recommendations based on efficacy studies.

APPENDIX B: SUMMARY OF EVIDENCE

# Appendix B Contents

lde	dentification and Assessment		
Visi	ion Screening Devices	195	
Α.	Photoscreeners	196	
В.	Photorefractors (a type of photoscreener)	197	
C.	Autorefractors	198	
Visi	ion Screening Tests and Programs	198	
A.	Random Dot E Stereotest (RDE)	199	
Ass	sessment Tests and Techniques to Assess Visual Function	200	
A.	Teller Acuity Cards (TAC)	201	
В.	Other tests	201	
Neu	uroimaging and Electrophysiologic Tests	202	
Inte	ervention Approaches	204	
A.	Promoting general development	205	
В.	Teaching motor skills, orientation and mobility	205	
C.	Vision stimulation	205	
D.	Parent participation	205	
De	velopmental Characteristics	206	
A.	Language and motor development	206	
В.	Play patterns and behaviors	206	
C.	Sleep patterns and disorders	207	

#### **IDENTIFICATION AND ASSESSMENT**

# **Vision Screening Devices**

This section evaluates the use of vision screening technology used to identify young children with specific vision impairments such as amblyopia. Topics include general photoscreeners, photorefractors, and handheld automated refractors (autorefractors).

#### **Studies Meeting Criteria for Evidence**

- 1. **Atkinson, J., Braddick**, O. J., Durden, K., Watson, P. G., and Atkinson, S. Screening for refractive errors in six- to-nine-month-old-infants by photorefraction. *British Journal of Ophthalmology* 1984; 68[2]: 105-112.
- 2. **Cooper**, C. D., Gole, G. A., Hall, J. E., Colville, D. J., Carden, S. M., and Bowling, F. G. Evaluating photoscreeners, II: MTI and fortune videorefractor. *Australian and New Zealand Journal of Ophthalmology* 1999; 27[6]: 387-398.
- 3. **Cordonnier**, M. and Dramaix, M. Screening for refractive errors in children: Accuracy of the hand held refractor Retinomax to screen for astigmatism. *British Journal of Ophthalmology* 1999; 83[2]: 157-161.
- Hamer, R. D., Norcia, A. M., Day, S. H., Haegerstrom-Portnoy, G., Lewis, D., and Hsu-Winges, C. Comparison of on- and off-axis photorefraction with cycloplegic retinoscopy in infants. *Journal of Pediatric Ophthalmology and Strabismus* 1992; 29[4]: 232-239.
- Hodi, S. Screening of infants for significant refractive error using videorefraction. *Ophthalmic and Physiological Optics* 1994; 14[3]: 310-313.
- 6. **Hope**, C., Roulston, J., Hoey, C., Wong, A., and Clover, G. Community photoscreening of six- to-nine-month-old infants for amblyopiogenic risk factors. *Australian and New Zealand Journal of Ophthalmology* 1994; 22[3]: 193-202.
- 7. **Ottar**, W. L., Scott, W. E., and Holgado, S. I. Photoscreening for amblyogenic factors. *Journal of Pediatric Ophthalmology and Strabismus* 1995; 32[5]: 289-295.
- 8. **Preslan**, M. W. and Zimmerman, E. Photorefraction screening in premature infants. *Ophthalmology* 1993; 100[5]: 762-768.

- 9. **Simons**, B. D., Siatkowski, R. M., Schiffman, J. C., Berry, B. E., and Flynn, J. T. Pediatric photoscreening for strabismus and refractive errors in a high-risk population. *Ophthalmology* 1999; 106[6]: 1073-1080.
- Tong, P. Y., Enke-Miyazaki, E., Bassin, R. E., Tielsch, J. M., Stager, D. R., Sr., Beauchamp, G. R., and Parks, M. M. Screening for amblyopia in preverbal children with photoscreening photographs. *Ophthalmology* 1998; 105[5]: 856-863.
- Tong, P. Y., Bassin, R. E., Enke-Miyazaki, E., Macke, J. P., Tielsch, J. M., Stager, D. R., Sr., Beauchamp, G. R., and Parks, M. M. Screening for amblyopia in preverbal children with photoscreening photographs, II: Sensitivity and specificity of the MTI photoscreener. *Ophthalmology* 2000A; 107[9]: 1623-1629.
- Tong, P. Y., Macke, J. P., Bassin, R. E., Everett, M., Enke-Miyazaki, E., Tielsch, J. M., Stager, D. R., Sr., Parks, M. M., and Beauchamp, G. R. Screening for amblyopia in preverbal children with photoscreening photographs, III: Improved grading criteria for hyperopia. *Ophthalmology* 2000; 107[9]: 1630-1636.
- 13. **Weinand**, F., Graf, M., and Demming, K. Sensitivity of the MTI photoscreener for amblyogenic factors in infancy and early childhood. *Graefes Archives for Clinical and Experimental Ophthalmology* 1998; 236[11]: 801-805.
- Williams, C., Lumb, R., Harvey, I., and Sparrow, J. M. Screening for refractive errors with the Topcon PR2000 Pediatric Refractometer. *Investigative Ophthalmology and Visual Science* 2000; 41[5]: 1031-1037.

#### **Panel Conclusions (Vision Screening Devices)**

#### A. Photoscreeners

- 1. Some photoscreeners (Medical Technology and Innovations, Fortune VRB) are not useful as general screeners in some samples because:
  - Too many children with risk factors for amblyopia are not identified
  - Photograph interpretation and grading can be subjective, leading to variation in results (Cooper 1999, Weinand 1998)
- When evaluating the efficacy of photoscreener results, a lack of information about pass/fail criterion and good statistical data analysis make it difficult to interpret study results (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).
- 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).
- B. 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 because one eye at a time is measured
  - Not commercially available and therefore not applicable for widespread screening (Atkinson 1984, Hamer 1992, Hope 1994)
- 8. The Visiscreen 100 is an outdated photorefractor. However, the following principles 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 with children younger than 36 months old because 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)

- C. 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 conditions (Cordonnier 1999).

### **Vision Screening Tests and Programs**

This section evaluates general and specific vision screening tests, and programs and components used to assess and identify vision impairments in young children.

The studies that met criteria for evidence were about grating acuity measurements. Although grating acuity measurements are important and routinely performed, it is a small part of assessment. Oculomotor functions, fixation, visual sphere, and eye-hand coordination were not evaluated.

#### **Studies Meeting Criteria for Evidence**

- Abrahamsson, M., Fabian, G., Andersson, A. K., and Sjostrand, J. A longitudinal study of a population based sample of astigmatic children, I: Refraction and amblyopia. *Acta Ophthalmologica (Copenhagen)* 1990; 68[4]: 428-434.
- Darlow, B. A., Clemett, R. S., Horwood, L. J., and Mogridge, N. Prospective study of New Zealand infants with birth weight less than 1500 g and screened for retinopathy of prematurity: Visual outcome at age 7-8 years. *British Journal of Ophthalmology* 1997; 81[11]: 935-940.
- 3. **Hope**, C., and Maslin, K. Random dot stereogram E in vision screening of children. *Australian and New Zealand Journal of Ophthalmology* 1990; 18[3]: 319-324.
- 4. **Johnson**, A., Stayte, M., and Wortham, C. Vision screening at 8 and 18 months. *BMJ* 1989; 299[6698]: 545-549.
- Marsh-Tootle, W. L., Corliss, D. A., Alvarez, S. L., Clore, K. A., Daum, K. M., Gordon, A., Houston, G., Perry, F. F., and Swanson, M. W. A statistical analysis of Modified Clinical Technique vision screening of preschoolers by optometry students. *Optometry and Vision Science* 1994; 71[10]: 593-603.
- 6. **Robinson**, B., Bobier, W. R., Martin, E., and Bryant, L. Measurement of the validity of a preschool vision screening program. *American Journal of Public Health* 1999; 89[2]: 193-198.

7. **Schmidt,** P. P. Vision screening with the RDE stereotest in pediatric populations. *Optometry and Vision Science* 1994; 71[4]: 273-281.

# Panel Conclusions (Vision Screening Tests and Programs)

- A. 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).
- 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 for having visual disorders by 2 to 3 times (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 (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 it is highly unreliable as a single test (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 because most of the children from the study ranged from 4 to 5 years old, and only 17% were <4 years old (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, 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, which 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 Tests and Techniques to Assess Visual Function

This section addresses the standardized and nonstandardized tests and methods used to assess and identify young children with vision impairment. Topics include Teller Acuity Cards (TAC) and other tests.

#### **Studies Meeting Criteria for Evidence**

- 1. **Birch**, E. E., and Hale, L. A. Criteria for monocular acuity deficit in infancy and early childhood. *Investigative Ophthalmology and Visual Science* 1988; 29[4]: 636-643.
- 2. **Cibis**, G. W., Maino, J. H., Crandall, M. A., Cress, P., Spellman, C. R., and Shores, R. E. The Parsons visual acuity test for screening children 18 to 48 months old. *Annals of Ophthalmology* 1985; 17[8]: 471-5, 478.
- Dobson, V., Quinn, G. E., Siatkowski, R. M., Baker, J. D., Hardy, R. J., Reynolds, J. D., Trese, M. T., and Tung, B., and The Cryotherapy for Retinopathy of Prematurity Cooperative Group. Agreement between grating acuity at age 1 year and Snellen acuity at age 5.5 years in the preterm child. *Investigative Ophthalmology and Visual Science* 1999; 40[2]: 496-503.
- Hall, H. L., Courage, M. L., and Adams, R. J. The predictive utility of the Teller acuity cards for assessing visual outcome in children with preterm birth and associated perinatal risks. *Vision Research* 2000; 40[15]: 2067-2076.
- 5. **Mash**, C. and Dobson, V. Long-term reliability and predictive validity of the Teller Acuity Card procedure. *Vision Research* 1998; 38[4]: 619-626.

- Mercuri, E., Haataja, L., Guzzetta, A., Anker, S., Cowan, F., Rutherford, M., Andrew, R., Braddick, O., Cioni, G., Dubowitz, L., and Atkinson, J. Visual function in term infants with hypoxic ischaemic insults: Correlation with neurodevelopment at 2 years of age. Archives of Disease in Childhood Fetal Neonatal Edition 1999; 80[2]: F99-104.
- 7. **Newman**, D. K., and East, M. M. Preschool vision screening: Negative predictive value for amblyopia. *British Journal of Ophthalmology* 1999; 83[6]: 676-679.
- 8. **Spierer**, A., Royzman, Z., Chetrit, A., Novikov, I., and Barkay, A. Vision screening of preverbal children with Teller acuity cards. *Ophthalmology* 1999; 106[4]: 849-854.

# **Panel Conclusions (Assessment Tests and Techniques to Assess Visual Function)**

- A. Teller Acuity Cards (TAC)
- 1. TAC is most accurate for 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)
- 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. When used to measure acuity in young children, TAC:
  - Has a high sensitivity and predictive value for identifying children with normal vision (Hall 2000, Mash 1998)
  - Is less sensitive for identifying children with abnormal vision (Hall 2000, Mash 1998)
  - Is less accurate than the Snellen letter charts (Mash 1998)
- B. 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)
- The Preferential Looking Procedure can be useful for 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 had 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. A child's failing three parts of the Atkinson Battery of Child Development for Examining Functional Vision (ABCDEFV) 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 with 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 administered in isolation, some children with amblyopia are not accurately identified (Newman 1999)

# **Neuroimaging and Electrophysiologic Tests**

This section evaluates the usefulness of special imaging and electrophysiologic tests for assessing young children with severe vision impairments. Two types of

imaging tests examined are magnetic resonance imaging (MRI) and cranial ultrasound. One type of electrophysiologic test, visual evoked potential (VEP), is examined.

These special assessment tests will typically be performed only for infants who appear either to have or are at high risk for significant neurodevelopmental problems. Such high-risk groups might include very premature and very low birth weight infants, and those who have experienced severe hypoxia at birth. Infants with abnormal neurological exam findings might also be considered for these special diagnostic tests. For these groups, the special assessment tests discussed below are sometimes performed to assess the infant's visual status or to predict the likelihood of future severe vision impairment.

# **Studies Meeting Criteria for Evidence**

- 1. **Cioni**, G., Fazzi, B., Coluccini, M., Bartalena, L., Boldrini, A., and Hof-van Duin, J. Cerebral visual impairment in preterm infants with periventricular leukomalacia. *Pediatric Neurology* 1997; 17[4]: 331-338.
- 2. **Clarke**, M. P., Mitchell, K. W., and Gibson, M. The prognostic value of flash visual evoked potentials in the assessment of non-ocular visual impairment in infancy. *Eye* 1997; 11[Pt 3]: 398-402.
- 3. **Mercuri**, E., Atkinson, J., Braddick, O., Anker, S., Cowan, F., Rutherford, M., Pennock, J., and Dubowitz, L. Basal ganglia damage and impaired visual function in the newborn infant. *Archives of Disease in Childhood Fetal Neonatal Edition* 1997; 77[2]: F111-F114.
- 4. **Pinto-Martin**, J. A., Dobson, V., Cnaan, A., Zhao, H., and Paneth, N. S. Vision outcome at age 2 years in a low birth weight population. *Pediatric Neurology* 1996; 14[4]: 281-287.

# Panel Conclusions (Neuroimaging and Electrophysiologic Tests)

- MRIs performed on 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 on 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 with 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

A limited number of intervention studies were found that met the criteria for evidence for the topics of interest for this guideline. Most of the studies address programs to promote general development or to facilitate development of motor skills, mobility, or orientation of children with vision impairment. One study that met criteria evaluated a program to stimulate visual development in infants.

#### **Studies Meeting Criteria for Evidence**

Promoting General Development

- 1. **Behl**, D. D., and Escobar, C. M. New Orleans early intervention study of children with visual impairments. *Early Education and Development* 1993; 4[4]: 256-274.
- Sonksen, P. M., Petrie, A., and Drew, K. J. Promotion of visual development of severely visually impaired babies: Evaluation of a developmentally based programme. *Developmental Medicine and Child Neurology* 1991; 33[4]: 320-335.

Teaching Motor Skills, Orientation, and Mobility

- 3. **Correa**, V. I., Poulson, C. L., and Salzberg, C. L. Training and generalization of reach-grasp behavior in blind, retarded young children. *Journal of Applied Behavior Analysis* 1984; 17[1]: 57-69.
- 4. **Harley**, R. K., Long, R. G., Merbler, J. B., and Wood, T. A. Orientation and mobility for the blind multiply handicapped young child. *Journal of Visual Impairment and Blindness* 1987; 81[8]: 377-381.

#### Vision stimulation

5. **Leguire**, L. E., Fellows, R. R., Rogers, G. L., Bremer, D. L., et al. The CCH vision stimulation program for infants with low vision: Preliminary results. *Journal of Visual Impairment and Blindness* 1992; 86[1]: 33-37.

# **Panel Conclusions (Intervention Approaches)**

- A. Promoting general development
- Because of a large drop-out rate and other study limitations, it is unclear
  whether children receiving vision training intervention perform better in
  tracking, looking, and "reaching and looking for familiar objects" than
  children not receiving vision training perform (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).
- B. 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).
- C. 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).
- D. Parent participation
- 8. There appeared to be no difference in child outcomes when parents are trained individually in the home compared to 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**

The studies of developmental characteristics that met the criteria for evidence fall into three categories: (1) language, motor, and general development, (2) play patterns and behaviors, and (3) sleep patterns and disorders.

# **Studies Meeting Criteria for Evidence**

- A. Language and motor development
- 1. **Hatton**, D. D., Bailey, D. B., Jr., Burchinal, M. R., and Ferrell, K. A. Developmental growth curves of preschool children with vision impairments. *Child Development* 1997; 68[5]: 788-806.
- Levtzion-Korach, O., Tennenbaum, A., Schnitzer, R., and Ornoy, A. Early motor development of blind children. *Journal of Paediatrics and Child Health* 2000; 36[3]: 226-229.
- B. Play patterns and behaviors
- 3. **Parsons**, S. The performance of low vision children on the Preschool Language Scale. *Education of the Visually Handicapped* 1985; 17[3]: 117-125.
- Parsons, S. Function of play in low vision children, II: Emerging patterns
  of behavior. *Journal of Visual Impairment and Blindness* 1986; 80[6]: 777784.
- 5. **Troester**, H., and Brambring, M. The play behavior and play materials of blind and sighted infants and preschoolers. *Journal of Visual Impairment and Blindness* 1994; 88[5]: 421-432.

- C. Sleep patterns and disorders
- 6. **Mindell**, J.A., and De Marco, C.M. Sleep problems of young blind children. *Journal of Visual Impairment and Blindness* 1997; 91[1]: 33-39.
- 7. **Troester**, H. Daily routines and sleep disorders in visually impaired children. *Early Child Development and Care* 1996; 119: 1-14.

#### **Panel Conclusions (Developmental Characteristics)**

- A. 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 who are blind are two different samples developmentally and may have different patterns of development (Hatton 1997).
- 6. Children who are blind experience delays in all areas of motor development when compared with standard milestone tables for children who are sighted (Levitzion-Korach 2000).
- 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 children who are blind when compared to normally sighted children (Parsons 1985).

- B. Play patterns and behaviors
- 8. Children with low vision who range from 2 to 4 years old 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 who range from 2 to 4 years old 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).
- C. 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. Because of incomplete data (low parent response and parental classification of impairments), it is unclear whether children with partial sight and multiple disabilities have a higher prevalence of sleep disorders compared to children who are blind (Troester 1996).

APPENDIX C: DEVELOPMENTAL ASSESSMENT TESTS

# APPENDIX C

# Appendix C Contents

Battelle Developmental Inventory (BDI)	211
Bayley Scales of Infant Development II (BSID-II) Second Edition (Third Edition Published 2005)	212
Carolina Curriculum for Infants and Toddlers With Special Needs (CCITSN)	213
Denver Developmental Screening Test: Denver II (DDST)	214
Hawaii Early Learning Profile (HELP)	215
Mullen Scales of Early Learning	216
Oregon Project for the Blind and Visually Impaired	217
Pediatric Evaluation of Disability Inventory (PEDI)	218
/ineland Adaptive Behavior Scales (VABS)	219

### **Battelle Developmental Inventory (BDI)**

Type of Test Criterion-based and norm-referenced with hearing norms using

verbal instructions and nonvocal responses. This is a measure of developmental skills across five domains. A screening test with 28% of the items included. Allows for multisource assessment.

Purpose To identify handicapped children, strengths and weaknesses of

nonhandicapped children, 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 subdomains. 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 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 (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. It 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 30-60 minutes

Standardization BSID normative data reflect the U.S. population in terms of

race/ethnicity, infant gender, education level of parents, and

demographic location of the infant.

The test 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)

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 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.

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 Evaluat	ion 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	Test is 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 (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 D: EARLY

INTERVENTION PROGRAM INFORMATION

New York State

#### D-1: EARLY INTERVENTION PROGRAM DESCRIPTION

The Early Intervention Program 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:

- Which early intervention services are appropriate 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 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
- Ensuring that children and their 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 program. This means that all children under three years of age who may need early intervention services must be referred to the EIO. In practice, Early Intervention Officials have staff assigned to receive child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the Early Intervention Official (see Step 1 of "Early Intervention Steps," page 228). 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 Early Intervention Official. The initial service coordinator helps with all the steps necessary to get services, ranging from the child's multidisciplinary evaluation to the first Individualized Family Service Plan (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 Early Intervention Program 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 impairment.

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 program. The child and family must be residents of New York State to participate in the Early Intervention Program.

### How is Eligibility Decided?

All children referred to the Early Intervention Official have the right to a free multidisciplinary evaluation to determine if they are eligible for services. The multidisciplinary evaluation also helps parents 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" as defined 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 Individualized Family Service Plan agreed to by the parent and the Early Intervention Official

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
- Nutritional 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--Services are provided to a child and/or parent or other family member or caregiver at home or 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--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--Parents and children receive services together in a group led by a service provider. A parent-child group can take place anywhere in the community.
- Family support groups--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--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 can take place anywhere in the community.

# REIMBURSEMENT

All services are at no cost to families. The program accesses Medicaid and commercial third party insurance when parents' policies are regulated by the state. County and state funds cover the costs of services.

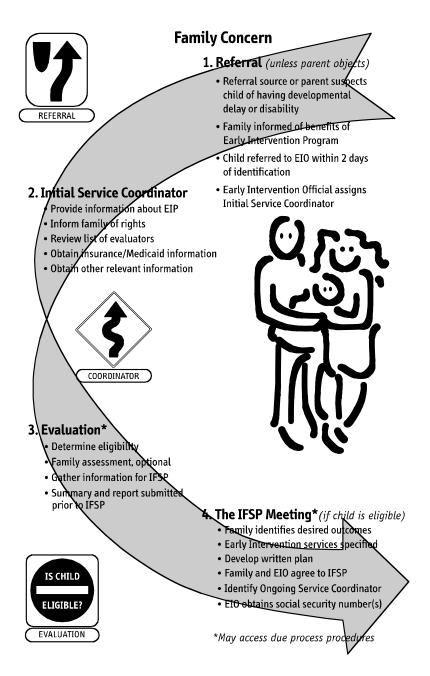
For more information about the New York State laws and regulations that apply to early intervention services, contact the Bureau of Early Intervention.

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.nyhealth.gov/community/infants\_children/early\_intervention/

bei@health.state.ny.us



#### 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



# **Areas of Development**

- cognitive
- physical (including vision and hearing)
- communication
- social/emotional
- adaptive development



# 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

Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.



Revised 12/04

#### D-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.nyhealth.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.
  - a. The following models of early intervention service delivery shall be available:
    - 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);
    - 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
      - 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:
  - the child's unique needs and strengths and the services appropriate to meet those needs; and
  - d. 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
    - 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:
  - 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
  - (a) the major outcomes expected to be achieved fro the child and the family, including timelines, and
  - (b) 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.

# D-3: TELEPHONE NUMBERS FOR MUNICIPAL EARLY INTERVENTION PROGRAMS

The following phone numbers were current at the time this document was published. Please visit our Web page for updates at

# http://www.nyhealth.gov/community/infants\_children/early\_intervention/

Albany	518-447-4820
Allegany	585-268-9247
Broome	607-778-2851
Cattaraugus	716-373-8050
Cayuga	315-253-1459
Chautauqua	716-753-4788
Chemung	607-737-5568
Chenango	607-337-1729
Clinton	518-565-4798
Columbia	518-828-4278 Ext. 1303
Cortland	607-756-3439
Delaware	607-746-3166
Dutchess	845-486-3403
Erie	716-858-6161
Essex	518-873-3500
Franklin	518-481-1709
Fulton	518-736-5720
Genesee	585-344-8506 Ext. 3
Greene	518-719-3600
Hamilton	518-648-6141
Herkimer	315-867-1176
Jefferson	315-785-3283
Lewis	315-376-5401
Livingston	585-243-7290
Madison	315-366-2361
Monroe	585-753-5437
Montgomery	518-853-3531
Nassau	516-227-8661
New York City	212-219-5213

Niagara	716-278-1991
Oneida	315-798-5549
Onondaga	315-435-3230
Ontario	585-396-4439
Orange	845-291-2333
Orleans	585-589-2761
Oswego	315-349-3510
Otsego	607-547-6474
Putnam	845-228-2847 Ext. 1036
Rensselaer	518-270-2625
Rockland	845-364-2620
Saratoga	518-584-7460 Ext.390
Schenectady	518-386-2815
Schoharie	518-295-8705
Schuyler	607-535-8140
Seneca	315-539-1920
St. Lawrence	315-386-2325
Steuben	607-664-2146
Suffolk	631-853-3100
Sullivan	845-292-0100 Ext. 1
Tioga	607-687-8600
Tompkins	607-274-6644
Ulster	845-334-5251
Warren	518-761-6580
Washington	518-746-2400
Wayne	315-946-5749
Westchester	914-813-5090
Wyoming	585-786-8850
Yates	315-536-5160
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APPENDIX E: 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	Tux (415) 501 0551
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 Blvd.	(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)	(602) 997 2210
PO Box 959 Fact Hammetond, NILL 02826, 0050	(603) 887-2310 (800) 473-2310
East Hampstead, NH 03826-0959 www.albinism.org	Fax (800) 648-2310
	1 ax (600) 040-2310
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 F: PEER

**REVIEWERS** 

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# SUBJECT INDEX

# **SUBJECT INDEX**

Adaptive/self-help skills assessment	87
Adaptive/self-help skills intervention	168
Albinism	25, 136
Amblyopia	25, 53, 136
Assessment	
adaptive/self-help skills	87
assistive technology	96
clinical clues	40, 43
cognition	77
communication	85
developmental assessment and tests	67, 71
electrophysiologic tests	64
family assessment	
general surveillance	
motor development	
motor developmental milestones	
ophthalmic examination	
orientation and mobility	
photoscreeners/photorefractors	
physical exam findings	
risk factors	41, 42, 47
screening	
sensory development	
social/emotional development	
vision tests	
visual acuity	
visual function	65
Assistive technology	96, 174
Autorefractors/photorefractors	56
Blindness, legal	22
Canes	149, 152
Cataract	25, 136, 139
Cognitive development assessment	77
Cognitive development intervention	156
Communication development assessment	85

Communication development intervention	165
Computerized Axial Tomography (CT or CAT)	63
Corneal opacities	138
Cortical visual impairment (CVI)	25, 42
Craniofacial anomalies	138
Developmental assessment	67
adaptive/self-help skills	88
cognitive	77
communication	85
motor	
sensory	
social/emotional	89
Developmental interventions	
adaptive/self-help skills	
cognitive	
communication	
motor	
sensory	
social/emotional	
Electrophysiologic tests	
Electroretinogram	
Evidence, methodology	7
Evoked potential	64
Eye anatomy	16
Eye conditions (ocular and visual disorders)	25
Family, assessment	108
Family, providing support	129, 133
Gene therapy	180
Glaucoma	
Hyperbaric oxygen	179
Intervention	
adaptive/self-help skills	
assistive technology	
cognitive	
communication	165
developmental	
evaluating options	

family support	129, 133
feeding/eating skills	
gene therapy	
general approach	
hyperbaric oxygen	179
light therapy	
medical/surgical	
motor	
nutritional/dietary supplements	
optical correction	
orientation and mobility	
planning and implementing	
questions when selecting	
sensory/motor	
sleep patterns	
social/emotional	
transplants/implants	
vision stimulation	
visual functioning	
Learning theories	
Light therapy	
Magnetic Resonance Imaging (MRI)	
Methodology, guideline	7
Motor development assessment	80
milestones	84
Motor development intervention	161
Neuroimaging	63
Nutritional/dietary supplements	180
Nystagmus	
Ocular and visual disorders	
Ocular motility	50
Ophthalmic examination	58
Optic nerve dysplasia/hypoplasia	25, 137
Optical correction	
Orientation and mobility	
Periventricular leukomalacia (PVL)	
Photorefractors/photoscreeners	
1 110101011u01010/pH01030100H013	

Preferential looking techniques	60, 61
Random Dot E Stereotest (RDE)	60, 62
Refraction/Refractive errors	59, 142
Retinitis pigmentosa (RP)	140
Retinoblastoma	25, 137
Retinopathy of prematurity (ROP)	25, 137, 140
Retinoscopy	59
Sensitivity/specificity	187
Sensory development assessment	80
Sensory development intervention	
Sleep patterns/disorderss	170
Snellen Test of Visual Acuity	
Social/emotional development assessment	
Social/emotional development intervention	171
Stereoacuity tests	
Strabismus	
Strength of evidence ratings	
Titmus Fly Stereotest	
Transplants/implants	
Ultrasound	
Vision	
defined	4, 16, 17
development	17, 19
ophthalmic exam	58
screening	53
tests	49, 59
Vision impairment	
causes	23, 136
defined	4, 20
identification	40
impact of	26
levels of severity	4, 20
ocular and visual disorders	25
Vision professionals	31
Vision stimulation	146
Vigual aquity	17 /0

# **INDEX**

Visual Evoked Potential (VEP)	64
Visual field	21, 49
Visual function assessment	65
Visual function intervention	143
Visual functions	21
Vitreo-retinal problems	140