

National Library Service for  
the Blind  
Library of Congress  
1291 Taylor Street, N.W.  
Washington, D.C. 20011  
202.707.5100; 202.707.0744  
(TTY); 800.424.8567  
<http://www.loc.gov/nls>

Prevent Blindness America  
500 E. Remington Road  
Schaumburg, IL 60173  
847.843.2020; 800.221.3004  
(Toll-Free)  
<http://www.preventblindness.org>

The Foundation Fighting  
Blindness  
(formerly the National  
Retinitis Pigmentosa  
Foundation)  
11435 Cronhill Drive  
Owings Mills, MD 21117-2220  
888.394.3937; 800.683.5551  
(TTY)  
410.568.0150; 410.363.7139  
(TTY)  
<http://www.blindness.org>

# CHILDREN WITH VISUAL IMPAIRMENTS

## Information for Parents

QUESTIONS

ANSWERS

RESOURCES

*Utah State Office of Education  
and Utah Parent Training and  
Information Center  
2007*



Patti Harrington, Ed. D.  
State Superintendent of Public Instruction  
250 E. 500 S., P.O. Box 144200, Salt Lake City, UT 84114-4200



### **Acknowledgement**

This booklet was created by a statewide task force of stakeholders including representatives from the Utah Parent Training and Information Center.

American Foundation for  
the Blind  
11 Penn Plaza, Suite 300  
New York, NY 10001  
800.232.5463 (Hotline)  
Publications: 800.232.3044  
<http://www.afb.org>

Blind Children's Center  
4120 Marathon Street  
Los Angeles, CA 90029  
323.664.2153; 800.222.3566  
<http://www.blindchildrenscenter.org>

National Association for  
Parents of the Visually  
Impaired, Inc.  
P.O. Box 317  
Watertown, MA 02472-0317  
617.972.7441; 800.562.6265  
<http://www.napvi.org>

National Association for  
Visual Impairments  
22 West 21st Street,  
6th Floor  
New York, NY 10010  
212.889.3141  
<http://www.navh.org>

National Braille  
Association, Inc. (NBA)  
3 Townline Circle  
Rochester, NY 14623-2513  
585.427.8260  
<http://www.nationalbraille.org>

National Braille Press  
88 St. Stephen Street  
Boston, MA 02115  
617.266.6160; 800.548.7323  
<http://www.nbp.org>

National Eye Institute  
31 Center Drive, MSC 2510  
Bethesda, MD 20892-2510  
301.496.5248  
E-mail: 2020@nei.nih.gov  
<http://www.nei.nih.gov>

National Federation of the  
Blind, Parents Division  
1800 Johnson Street  
Baltimore, MD 21230  
410.659.9314, ext. 360  
<http://www.nfb.org/nopbc.htm>

## Resources

American Foundation for the Blind. Search AFB's Service Center on the Web to identify services for blind and visually impaired persons in the United States and Canada.

<http://www.afb.org/services.asp>

Holbrook, M.C. (Ed.). (1996). Children with visual impairments: A parents' guide. Bethesda, MD: Woodbine. Telephone: 800.843.7323; 301.897.3570.

<http://www.woodbinehouse.com>

Lewis, S., & Allman, C.B. (2000). Seeing eye to eye: An administrator's guide to students with low vision. New York: American Foundation for the Blind.

Telephone: 800.232.3044.

<http://www.afb.org>

National Eye Institute, eye health organizations list.

<http://www.nei.nih.gov/health/resourceAlpha.asp>

## Organizations

Utah Parent Training and Information Center

Utah Parent Center

2290 East 4500 South,

Suite 110, Salt Lake City,

UT 84117-4428

Phone: 801.272.1051

Fax: 801.272.8907

Toll-Free: 800.468.1160

Español: 801.272.1067

American Council of the Blind

1155 15th St. N.W.,

Suite 1004

Washington, D.C. 20005

202.467.5081; 800.424.8666

<http://www.acb.org>

## Primer for Parents of Children With Visual Impairments



The purpose of this booklet is to provide parents who have a child with visual impairments with information regarding vision with loss and its possible impact on education.

### Characteristics of Vision Loss

The following are some characteristics young children may exhibit that could indicate a visual loss. A professional should be consulted if your child is experiencing one or more of these symptoms:

- **Appearance of the Eyes**
  - Drooping eyelid that obscures the pupil
  - Abnormalities in the shape or structure of the eyes
  - Absence of a clear, black pupil
  - Persistent redness of the white part of the eye
  - Persistent tearing without crying
  - High sensitivity to bright light indicated by squinting, closing eyes, or turning away
- **Unusual Eye Movements**
  - Jerky eye movements
  - Absence of eyes moving together or sustained eye turn after 4–6 months of age
- **Unusual Gaze or Head Positions**
  - Tilts or turns head in certain position when looking at objects.
  - Holds object close to eyes.
  - Averts gaze or seems to be looking beside, under, or above the object of focus.

- **Absence of the following Visually Directed Behaviors**
  - Eye contact by three months
  - Visual fixation or following by three months
  - Accurately reaching for objects by six months
- **High-Risk Factors**
  - Family history of vision impairments and/or blindness
  - Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes, chicken pox)
  - Abnormal prenatal brain development
  - Prematurity
  - Congenital visual syndromes
  - Bacterial meningitis
  - Head trauma
  - Cerebral palsy



Adapted from material developed by Teresa Coonts, Nebraska Deaf-Blind Project.

### ***Educational Setting***

The terms partially sighted, low vision, legally blind, and totally blind are used in the educational context to describe students with visual impairments.

- **Partially sighted** indicates some type of visual problem that has resulted in a need for special educational accommodations.
- **Low vision** applies to all individuals with sight who are unable to read the newspaper at a normal viewing distance, even with the aid of eyeglasses or contact lenses. The child may use a combination of vision and other senses to learn, although they may require adaptations in lighting or the size of print, and sometimes Braille.
- **Legally blind** indicates that a person has less than 20/200 vision in the better eye or a very limited field of vision (20 degrees at its widest point).

Children naturally learn to play with toys, crawl, walk, use all their senses to explore their world, and build relationships with those around them. For a child with vision impairment, these and other areas of development may be affected. Because vision plays a major role in the developmental process, the early intervention vision consultant will develop a curriculum to meet the child's unique needs.

Activities and strategies may include, but are not limited to, those listed below:

- Helping the child learn to use remaining vision
- Tactile awareness
- Pre-literacy
- Orientation and mobility
- Communication/language
- Cognition and play
- Independence with self-help skills

### **Where are PIP services provided?**

PIP will provide sensory services in the child's **natural environment** determined appropriate by the IFSP team. Natural environments are the places where young children experience everyday, typically occurring learning opportunities that promote and enhance behavioral and developmental competencies. Examples of natural environments include home, day care, toddler classes, nurseries, community parks, eating establishments, etc.

### **How do I contact PIP?**

Ogden: 801-629-4743  
 Salt Lake: 801-464-2000  
 Statewide: 800-990-9328

### **Who can receive PIP services, and how is eligibility determined?**

The population served by the Blind PIP division of the Parent-Infant Program consists of children birth to three years of age that are diagnosed with a significant vision impairment that affects their development. Eligibility is determined by the infant or toddler's vision diagnosis, degree of vision loss, and ability to use remaining vision. This eligibility determination is based on the early intervention vision consultant's formal and informal assessments, clinical report by an ophthalmologist, and parental reports. If clinical assessment is not available or is inconclusive, PIP may rely upon informed clinical opinion based on all available information.

### **What are some of the instructional strategies used by PIP?**

Parent-Infant Program goals include the following:

- Become familiar with the vision diagnosis and learning needs of the infant/toddler.
- Develop a process for gathering and sharing vision information with the family and other early intervention providers.
- Implement vision programming and strategies with the family that address the specific learning needs of the family/toddler that best fit within the family's routines.
- Support the parent-infant relationship.
- Offer specific vision activities and suggestions for promoting the child's development.
- Assist the infant/toddler to learn essential skills needed to foster independence.
- Help the child develop skills to achieve his/her fullest potential.
- Provide parent-to-parent support.
- Provide information on local, state, and national vision resources.
- Provide assistance in planning for transition to preschool.

- **Totally blind** will require learning Braille or other non-visual media.

### ***Impact on Education***

A young child with visual impairments could have little reason to explore interesting objects in the environment, and thus, may miss opportunities to have experiences and to learn. This lack of exploration may continue until learning becomes motivating or until intervention begins.

Because the child cannot see parents or peers, he or she may be unable to imitate social behavior or understand nonverbal cues. Visual impairments can create obstacles to a growing child's independence.

Children with visual impairments should be assessed early to benefit from early intervention programs, when applicable. Technology, in the form of computers and low-vision optical and video aids, enables many partially sighted, low vision and blind children to participate in general class activities. Large print materials, audio books, and Braille books are available.



Students with visual impairments may need additional help with special equipment and modifications in the general curriculum to emphasize listening skills, communication, orientation and mobility, vocational/career options, and daily living skills. Students with low vision may need help using their residual vision more efficiently and working with special aids and materials.

## ***Frequent Questions/Answers***

There are a number of questions you may have as a parent of child with a visual impairment. The following set of questions is adapted from materials from the American Foundation for the Blind.

### **1. If my child is visually impaired, what may I expect?**

Your child may do things differently from other children—such as getting really close to look at a book—and may learn some things faster than others—such as memorizing riddles and songs.

Your child will learn about sounds as he/she grows older, but will need help in identifying them and understanding which are important for safety. The same holds true for learning new games and sports. A visually impaired child can learn to swim, for example, if someone will move his/her arms to help him/her gain a feel for the movement of swimming.



Expect your child to:

- Be curious, question, and listen.
- Get close to objects.
- Need to be shown how to do things.
- Be unaware of what they cannot get close to.

### **2. Can my child be successful?**

Many children and adults who are totally blind and are successful; they learn, love, work, and have families. The teenager or adult your child becomes depends largely on what you do as a parent.

- Teach your child to take responsibility.
- Expect your child to succeed.
- Expect your child to do things independently.

For children of or close to school age, contact your school district, state department of education, or the state parent information and training center.

## ***Parent-Infant Program***

The Parent-Infant Program (PIP) at the Utah Schools for the Deaf and the Blind incorporates family-centered practices into services for families and children birth to three with vision or hearing loss. PIP recognizes that early identification and services for children with sensory loss can significantly optimize developmental potential. PIP is a home-based program, fostering activities in a variety of natural settings using developmentally appropriate practices. The Parent-Infant Program strives to:

- Support parents in their efforts to understand their child's vision loss.
- Support parents in understanding their child's unique needs.
- Provide resources to parents to prepare their child for further education.
- Provide early intervention vision services in coordination with other service providers within each local early intervention program.

Baby Watch Early Intervention and the Utah Schools for the Deaf and the Blind Parent Infant Program collaborate in provision of services through interagency agreement.

vision to tell where we are. Your child will rely on hearing, touching, and smell more than normal.

Cover your eyes and try walking around your own home and other familiar places. Pay attention to the sounds, smells and feel of a place that tell you where you are. These are clues for your child to learn through exposure and repetition about his/her surroundings and you can help.

#### 10. What will happen when my child goes to school?

Every child with a visual impairment is entitled to a free appropriate public education. This means that the type of education a child receives depends on what the child's needs are at any point in time.

You are part of a team that will discuss and plan for your child's education through an Individual Education Program that outlines the services and location where your child can best learn. There are many types of technology available to help children with visual impairments in classrooms, including computers and low-vision optical and video aids. Large-print materials, audio books, and Braille books are available. Students with visual impairments may need additional help with special equipment and modifications in the general classroom to emphasize listening skills, communication, orientation and mobility, vocational/career options, and daily living. Students with visual impairments combined with other types of disabilities have a greater need for an interdisciplinary approach and may require greater emphasis on self-care and daily living skills.

#### 11. Where can I go for help?

Many public and private agencies have programs for assistance. To find out what is available in your community, talk with a doctor or eye specialist. For infants and toddlers, ask for referrals to an early intervention program, where you will be placed in touch with professionals to assist you in finding services and professionals for very young children with visual impairments and their families.

- Remember that some learning does not come naturally.
- Actual experiences have more value than descriptions of experiences.
- Don't wait for the world to come to your child.

What seems ordinary may need to be explained (e.g., scrambled, fried, and hard-boiled eggs all start out as raw eggs). Some events will need to be explained (tell your child about a bird flying and let him/her have the chance to touch or hold one). Your child may need help putting parts together to form a whole (he/she cannot touch an entire dog at one time, but can feel the nose, ears, paws, and tail separately). You can then help him/her figure out how the separate parts make a whole dog.

#### 3. Why does my child seem slower than other children?

Your child will have a different way of learning, since the opportunities and chances for learning are fewer because of the visual impairment. That does not mean you child cannot learn; it means your child will depend on you and others to teach and show him/her what he/she cannot learn naturally.

#### 4. Why doesn't my child move very much?

Very young children learn to crawl and walk because they see something across the room they want, or because they watch people around them moving. If your child cannot see an object, he/she probably does not know the object is there, and therefore has no reason to go get it.

As a result, it's tempting to try to bring experiences to your child, but you won't always be there for your child. What you can do is encourage your child to be curious, to explore, and to discover the world around him/her. Seek out opportunities to help your child



learn that people and objects exist even when he/she is not touching or hearing them. Show your child how to crawl, walk, run and jump. Get on the floor with him/her and put him/her through the movements until he/she knows what crawling is and can do it independently.

**5. What if my child doesn't play with toys?**

Until children know what a toy is and how to use it, they won't have a very good idea of how to play with it. Adults often buy toys for children because we, the adults, like the colors, the sounds, or shapes. Children with visual impairments often don't know the toys are there, and need the help of adults to discover toys.

**6. Why does my child do some things repeatedly?**

Children with visual impairments can develop habits like rocking or eye poking that can be aggravating to you as the adult. The best approach is to change the habit by correcting your child, reminding him/her about what he/she is doing or shifting his/her attention to some other activity. You must be consistent and persistent.



**7. Why does my child repeat everything I say?**

All children go through a stage of repeating or echoing what people say. This is called echolalia. It's a way of practicing speech and learning about language and communication. With blind or visually impaired children, this stage can seem to last longer. Words stand for real people, concepts, and objects. Until a child understands that, he/she will not be able to put words together to make his/her own speech. Repeating someone else's words is easier.

You can help your child move to using language by being careful about how you use language. Consider the following:

- Am I just naming things for my child, or am I describing them, talking about them, and relating them to other events in my child's life?
- Am I just repeating words my child says, or do I add a little more information each time?
- Am I asking my child too many questions?
- Do I give my child a chance to answer the questions that I do ask?
- Do I anticipate what my child wants, or do I wait for my child to tell me (by words or actions) what he/she wants?

**8. Why does my child walk "oddly"?**

Many parents have noticed that their child with visual impairments may walk or shuffle with his/her feet wide apart and/or toes pointed slightly out to the side. They worry that their child may never walk like other children.

Most children walk like this when they first are learning to walk. They do this because it helps them keep their balance. As they become better walkers, they no longer need such a wide base of support. Confidence comes with lots of movement activities from infancy. A very young child with visual impairments especially needs you to help stay physically active in order to learn about how the body moves and how it feels to move about. Help him/her experience rolling over, reaching, twisting, and crawling, which are all activities that lead to walking.

**9. How will my child know where he/she is physically?**

If you have not experienced a visual impairment, it may be difficult to imagine how your child will learn where he/she is physically. Most of us rely on

