Vision is a unifier of experience and the primary learning mode of infants and toddlers. Since 85% of early learning is visual, children who are blind or have severe visual impairments have large gaps in their understanding of the world. They experience disconnected sounds, tastes, smells and other sensations and must learn to use their other senses to fully integrate the information they receive. Their parents and other caregivers must fill in the visual gaps and bring the world to them through real life experiences, so they can begin to interact with and to interpret the world around them.

Infants and toddlers with visual impairments often experience many medical visits during the first three years of their lives as their diagnosis and treatment plans are refined. This fact sheet provides guidelines and strategies for medical professionals and families to follow to most fully accommodate the child during these visits. The needs of the medical professional and the family are addressed separately, although both will need to work together in partnership to most effectively adapt the environment for the child. Health professionals contribute their medical expertise to the partnership and parents contribute their intimate knowledge and understanding of their child.

To The Medical Professional

Because infants who are born blind or severely visually impaired are rare in the general population, many pediatric medical professionals can practice for years without seeing a visually impaired infant in a clinical setting.

Children with visual impairments may go to many medical specialists including ophthalmologists, neurologists, optometrists and ocularists in addition to their pediatricians. Professionals in medical settings may overlook the unique needs of these children when they treat the child for other disability or health concerns.

Additionally, because visually impaired babies often lag behind their sighted peers on developmental milestones, professionals may label them as delayed when in fact they are developing within a normal range for children with visual impairments. For example, while a typically-sighted baby may lie in the prone position with her head up and reach for an object at 3-5 months, an infant with a visual impairment may not do this until 9-12 months. Lacking vision to see an object, the child has no motivation to reach for it until she learns through other experiences that something is there.

In treating these young patients, please keep in mind that their parents have only recently been thrown into a medical world for which they are unprepared. One parent likened it to “falling into a huge medical abyss. I didn’t understand half the words the doctor rattled off and I was too scared to ask questions.” The chief complaint from
parents about working with the medical community is a sense that their observations are not taken seriously by some medical specialists:

“Being heard is the single most important idea. Every time I had a conflict, it was about needing to be heard,” said one parent.

It is most helpful when medical professionals can take the time to offer an empathic response to parents, remembering that what is familiar to medical personnel is often strange and frightening to families.

Adaptations During Medical Visits

Environmental adaptations for children with visual impairments vary depending on the cause and the degree of vision loss in addition to other possible disabilities.

Strategies to consider include:

- Provide a waiting room equipped with brightly colored toys that light up or make interesting sounds and books with high contrast, simple pictures (see Resource List).
- Always address the infant or toddler by name. Touch her when you are speaking to her. This keeps her engaged and lets her know she is part of the process.
- Introduce yourself and any medical staff who come in with you. Briefly explain your roles. Optimally, each person would say her name as he touches the baby to say hello.
- Give the infant a transition time before starting an exam or procedure. Use a brightly-colored toy or a favorite toy brought from home. Let the toddler explore the exam room to familiarize herself with the environment. Lacking vision, she cannot see the room like sighted infants or toddlers. She needs to “see” it with her hands, as possible.
- Position the infant to encourage participation or responsiveness to the test or procedure. Sometimes positions which promote the best physical development do not promote efficient use of residual vision. Try several positions, for example over the mother’s shoulder, on her tummy, on her back or in an infant seat.
- Be aware of the light source in the room and position the baby in a way that reduces glare and allows her to best utilize her vision. For optimal results, position the light source behind the child.
- Let the child feel or touch any instrument before using it. A typically-sighted child sees a doctor pick up an otoscope and bring it to her ear. Without a verbal and tactile cue, the child with a visual impairment experiences a strange, pointed object suddenly placed in her ear.
- If you want the baby to reach for an object, tap it on the back of the baby’s hand so she knows to reach for it.
- Talk with the child before starting each procedure.
- Describe what is happening, including any extraneous noises the baby might hear.
- Use tactile and auditory prompts if you need the infant to participate in the exam.
• Brightly-colored toys that make a sound are best.
• Provide positive feedback through tone of voice and by touching the baby.
• Slow down the pacing of the procedure or activity. An infant with a visual impairment often takes longer to respond, even when she understands what to do.
• Develop consistent cues to indicate a transition from one treatment or activity to another.
• If the child becomes upset during the procedure, take a break long enough for the parent to help the child calm down.
• Let the baby know when the procedure is over.
• Always remember that a child is not a small adult. Don’t expect adult behavior.

Behaviors or Characteristics You May Observe
Blind or visually impaired infants often respond to new or scary situations by “pulling in,” holding their head down, becoming very quiet. This is a way to assess what is going on, to listen to the new sounds and environment and try to make sense of it. They are not necessarily withdrawn or noncommunicative. They are paying attention.

To the Family
You are the primary environmental mediators for your child. If a medical professional is not familiar with the needs of infants and children with visual impairments, make suggestions regarding the most appropriate way to interact with your child. Review the suggestions in this fact sheet and develop a list specific to your child’s needs. You may also need to take a proactive role in making sure that your child’s needs are accommodated during medical appointments. Always keep in mind that you are the consumers in this relationship, and that you have a right to ask for clear explanations. There is no such thing as a “stupid” question; understanding the information may be critical to obtaining the proper diagnosis and most appropriate treatment for your child.

Preparation
Perhaps the most important thing you can do to make a medical visit more productive and less stressful for both you and your child is to prepare for it. Try some of the following suggestions:
• Schedule appointments for times when your baby or child is at her best.
• Consider asking for the first appointment of the day, especially in clinic settings.
• Keep all pertinent medical information in one place. Put it in a loose leaf binder with tabs. Include tabs for diagnosis, doctors reports, agency information, a divided plastic sheet to insert professionals’ business cards, a few loose leaf pages for notes and a schedule of medications.
• Prepare a list of questions you want to ask the doctor. Include this in your notebook or file folder.
• Keep a log of new or difficult to diagnose behaviors, if necessary. Consider making a video tape of the behaviors to show the doctor.

• Bring along a book or activity that demonstrates your child's ability to see.

• Pack a diaper bag with the baby's medical binder, extra food for your baby and for yourself, toys and books (always include a special comfort toy), extra diapers, activities for siblings and extra medication, if necessary.

• Arrange for child care for siblings, if possible. If child care is not available, bring a support person to take notes or help with siblings.

• Bring a tape recorder and tape the session to refer to later if you can’t bring a support person with you.

• Prepare your child for the visit (see upcoming section).

**Strategies During the Medical Appointment**

• When you check in, be sure to let the receptionist know if you need to leave at a specific time.

• Talk to your child about what’s happening in the waiting room and who is there.

• Hold the baby, or at least hold her hand, to keep her engaged so she won’t feel isolated. Explain extraneous noises—like a child crying.

• Bring out a favorite toy when the doctor arrives and let him use it to play with the baby. The doctor can use it later to get the baby to respond during the exam.

• Bring out your list of questions. Have your support person take notes or tape record the session so you can refer back to it later.

• If the doctor does not explain a procedure, stop him from proceeding with the exam. Ask that he explain the procedure as simply as possible, so the child can anticipate what will happen.

• Develop a consistent cue to let your child know an unpleasant procedure, such as a needle stick or an eye drop, is about to happen. A simple verbal cue such as “This will hurt a little,” helps her prepare for the hurt. Afterward, say, “All done.”

• Develop a list of adaptations specific to your child’s visual and physical needs and give it to medical professionals who work with your child on a regular basis.

**Preparing for Medical Procedures**

Your composure as a parent is essential. Nothing calms a child more than a confident parent. Although it is natural for you to feel anxious when your child is about to have a painful or scary procedure, it is best not to convey this to your child.

• Check with the doctor’s office to find out how the procedure is performed.

• For infants, stay with the baby throughout the procedure. When this is too difficult for you, try to find another family member or friend with whom the baby feels comfortable.
• If your child is older, talk and walk through the steps from the child’s perspective. A typically developing child’s receptive language is in place by eighteen months of age. Don’t underestimate the young child’s ability to understand what you are saying, particularly if you use simple pictures or props.
• Talk about the kinds of medical instruments that may be used. If you have access to the actual instruments ahead of time, let the child touch and play with them.
• Some hospitals offer training for the procedure for young children with puppets, miniature instruments and even a visit to the O.R. or M.R.I. room. These trainings can be effective for 2-3 year olds.
• If a needle stick is required to draw blood or place an I.V. line, request a topical anesthetic which deadens the top layer of skin and makes this type of procedure much less painful.
• Read picture books to the child on what to expect at the doctor’s office.
• Help your child act out or rehearse what happens during the procedure for five minutes a day for a few days prior to the procedure. She may be calmer knowing what to expect.
• Don’t assume that the procedure will be done in the same way each time. Call ahead to confirm.

**Please note:** In the interests of gender equality and readability, the personal pronouns “he” and “she” have been used alternately within the fact sheet. The term "visual impairment” was chosen as it includes all levels of vision loss.

**Glossary**

**Neurologist:** A medical doctor (M.D.) trained in the diagnosis and treatment of diseases of the nervous system

**Ocularist:** A professional who specializes in the fitting and making of artificial eyes

**Optician:** A professional who specializes in grinding lenses and dispensing eyeglasses as prescribed by ophthalmologists or optometrists

**Optometrist:** A professional who specializes in the assessment and treatment of vision problems and prescribes eyeglasses, contact lenses and eye coordination training activities

**Ophthalmologist:** A medical doctor (M.D.) who specializes in diagnosing and treating diseases of the eye and may include prescribing eyeglasses, contact lenses, medications and surgery

**References**


**Resources**


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Blind Babies Foundation believes in the importance of equity of access to information for individuals who are blind or visually impaired.

These materials are available in alternative formats including electronic text.

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