

State of Illinois
Rod R. Blagojevich, Governor

Department of Human Services
Carol L. Adams, Ph.D., Secretary



SUPPORTING FAMILIES:



**AN ILLINOIS RESOURCE GUIDE FOR FAMILIES OF
YOUNG CHILDREN WHO HAVE A COMBINED
VISION AND HEARING LOSS**

A SPECIAL THANK YOU TO SARAH PETTY PHOTOGRAPHY FOR DONATING THE COVER PHOTOGRAPH.
SARAH PETTY PHOTOGRAPHY
SPRINGFIELD, ILLINOIS



WHEN A COMBINED VISION AND HEARING LOSS IS FIRST DIAGNOSED parents often report feelings of shock. These feelings later turn to disbelief, grief, and anger. As time passes, families begin to search for help. We can get many questions answered from the internet. But, local information and resources are hard to find. Use this booklet to help you find those people and resources that will bring the support you need on a daily, personal level.

MEETING MY CHILD'S NEEDS

You may be feeling a sense of alarm. You may wonder how your child will learn basic information when vision and hearing are compromised. How will he learn to find his toys and engage in play? How will he learn to communicate? While these questions are valid, they are manageable. Children with combined vision and hearing loss can learn to accomplish almost any task you can imagine. As their parent, you will be their primary teacher. But, there are avenues of support available to you.



FINDING SUPPORT

A child suspected of having a dual sensory loss should be seen and treated by medical eye and ear doctors. Some eye problems, if left untreated, can have negative long-term effects on a child's vision. Prompt attention to eye problems may increase the speed and effectiveness of treatment. Hearing loss, if not detected or treated, can result in a high risk for delayed speech and language development. A dual sensory impairment can cause severe communication and developmental delays.

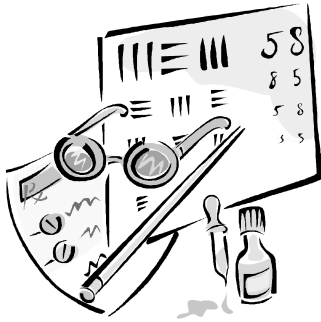
The **Division of Specialized Care for Children (DSCC)** can help eligible families find and pay for services from an approved ophthalmologist and audiologist. They can also help pay for appointments related to diagnosis and for medical treatment of some conditions related to vision and hearing. Contact DSCC at 800-322-3722 to find out if you qualify. Visit them on the web at www.uic.edu/hsc/dsc.

When a child has a diagnosed combined vision and hearing loss, he is at high risk for communication and developmental delays. But, research has shown that we can decrease or avoid these delays. We must provide young children with the proper play opportunities with supports. Families of children with a dual sensory loss can receive help through the



Illinois Early Intervention System (EI). A number of different services and therapies are available. These services are usually provided in your home. To find out more, contact your local **Child and Family Connections** agency. Their location information can be found on page 14 of this booklet. To find a specialist to offer inservice training on intervention techniques for service providers and families of combined vision and hearing losses, contact **Project Reach: Illinois Deaf-Blind Services** at 630-790-2474 (Voice) or 800/771-1158 (TTY).

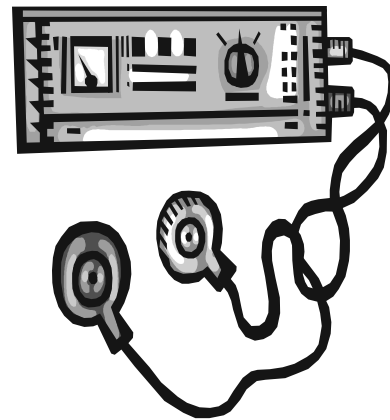
FINDING THE SPECIALISTS



Optometrists and Ophthalmologists are medical eye care professionals. An **Ophthalmologist** is a surgical doctor who diagnoses and treats pathological conditions of the eye such as glaucoma, cataracts, and retinal diseases. An **Optometrist** is a primary health provider who examines, diagnoses, and treats diseases of the eye. One such treatment could include Vision Therapy.

Vision therapy must be conducted by an eye care professional. Some Optometrists specialize in low vision care. This service emphasizes the enhancement of remaining vision beyond ordinary glasses or contact lens prescriptions and may be appropriate for some children with vision impairment.

An **Otologist** specializes in problems of the ear and offers appropriate treatment. An **Audiologist** is a specialist with a degree in audiology. The audiologist has the basic responsibility for assessing hearing, determining auditory capacity, and for increasing the ability of individuals with hearing losses to adjust to the situations of everyday life.



A **Developmental Therapist Vision** (DTV) and a **Developmental Therapist Orientation and Mobility** (DTO&M) are the educational professionals who attend to developmental delays caused by a lack of vision. The DTV will help a child learn about his environment. The DTV will teach the child how he can use his remaining vision and other senses to learn and interact with his world. A DTO&M works to help a child orient in his environment and move safely within that space. To learn more or to obtain help in finding one of these specialists in your area contact **Hearing and Vision Connections** at 217/479-4324 (V/TTY). Visit them on the web at www.morgan.k12.il.us/isd/hvc.

A **Developmental Therapist Hearing** (DTH) is a credentialed Early Intervention provider with a degree in Deaf Education. This professional provides services related to auditory functioning, sign language instruction, independent living skills training, use of assistive technology (such as hearing aids), and additional training necessary to stimulate communication. To find a DTH in your area contact **Hearing and Vision Connections** at www.morgan.k12.il.us/isd/hvc or call 217/479-4319 (V/TTY).



MEETING MY NEEDS AS A PARENT

As a parent, you are your child's best support, advocate, and teacher. You will be the single biggest influence in his life. What an incredible responsibility and privilege! We look to past experiences to develop our own sense of what to do as a parent. We read books and magazines to learn the newest advice on parenting. But, when your child has a combined vision and hearing loss, parenting models and information become harder to find. In most situations we parent our child the same whether he has a dual sensory impairment or not. But, sometimes we want ideas from others who have children who have combined sensory losses. Chances are great that you don't know any other child or family with a dual sensory loss. Illinois is a state with many helpful resources available.

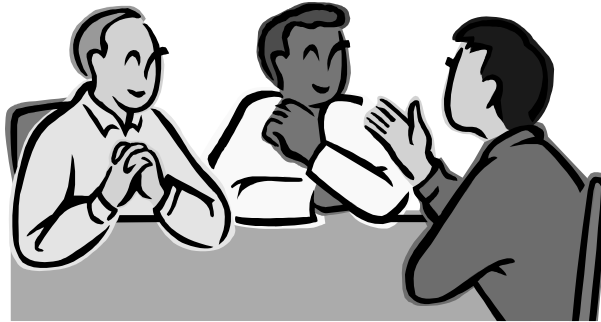


FINDING OTHER PARENTS

Illinois Advocates for the Deaf-Blind is an organization of parents, families and friends dedicated to protect the rights and advocate for the needs of all individuals who have a combined sensory impairment. For more information, contact kjo@bradley.edu.

National Family Association for Deaf Blind (NFADB) is the largest national network of families focusing on issues surrounding deaf-blindness. For more information, contact by phone at 800/255-0411 or visit the web at www.nfadb.org.

Illinois Parents of the Visually Impaired (IPVI) is a very active parent group. They produce a monthly newsletter and have regularly scheduled outings. Parents have the chance to get to know one another. IPVI also develops an incredible resource guide. This guide is made available to their members each year. For more information, contact by phone at 877/411-4784 or visit the web at www.ipvi.org.



Illinois Families for Hands and Voices is a parent-driven organization dedicated to providing non-biased support to parents of children who are deaf or hard of hearing. For more information, contact support@ilhandsandvoices.org.

The **Parent Infant Institute** (PII) is another great way to meet with other parents. This three-day event is held at the **Illinois School for the Visually Impaired** and at the **Illinois School for the Deaf** each June. Families attend at no cost. Parents attend workshops to learn about impact of vision and hearing loss. Children receive developmental evaluations. But, parents say that the greatest benefit is meeting other parents. Contact the **Illinois School for the Visually Impaired** at 217/479-4400 or the **Illinois School for the Deaf** at 217-479-4200 (V/TTY) for more information. Visit them on the web at www.isvi.net or www.morgan.k12.il.us/isd.



EDUCATION AND INFORMATION



Start with **Project Reach: Illinois Deaf-Blind Services** when you are looking for information. Each Deaf-Blind Specialist with Project Reach has broad experience with children of all ages with dual sensory loss. She can answer questions about your child's

impairment. She can bring you books and resources related to your questions. If there are other families in your area whose members have a combined loss, she probably knows them and can introduce you. Project Reach provides technical assistance, consultation, information, training, and family support to address the needs of children who have a combined vision and hearing loss. Contact them at 630/790-2474 (Voice) or 800/771-1158 (TTY). Visit **Project Reach** at <http://project-reach-illinois.org>.

DB-LINK is a national information clearinghouse on children who are considered deaf-blind or dually sensory impaired. They have a comprehensive library of topics, including causes and characteristics of deaf-blindness. The DB-Link staff is available to help you use the database and obtain publications. DB-LINK also offers email discussion groups, training activities, people and program finders and more. Contact by phone at 800/438-9376 (Voice) 800/854-7013 (TTY) or visit DB-Link on the web at <http://www.dblink.org>.

Another local resource is your child's **Developmental Therapist Vision (DTV) or Developmental Therapist Hearing (DTH)**. She can provide continued support and information. If you need help finding a DTV or DTH in your area, call Hearing and Vision Connections at 217/479-4318 (V/TTY).



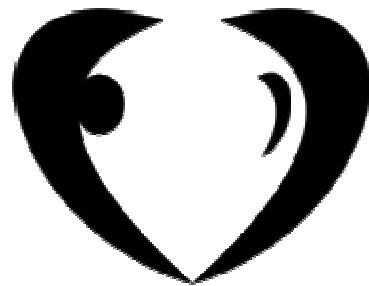
Many families around the world have benefited from the free services available through the **Hadley School for the Blind**.

Illinois is proud to be the home of this incredible organization. Hadley offers in-depth courses on a variety of topics. They have a track of classes specifically designed for new parents. Family members can take these classes at their own pace from home. Find out more about the Hadley School for the Blind by calling them at 800/323-4238. Visit them on the web at www.hadley-school.org.

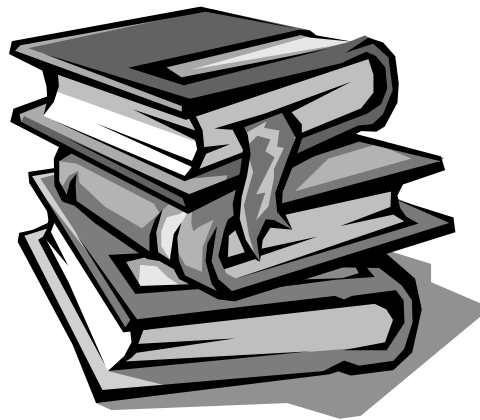
Hadley also recognizes the **John Tracy Clinic**, which offers hope, guidance, and encouragement to families of infants and preschool children with hearing losses by providing free, parent-centered services worldwide. They extend parent distance education sessions for families of young children ages 0-5 years with hearing loss. A special course is available for parents of preschool children with a deaf-blind or dually sensory impaired diagnosis. Contact by phone at 213/748-5481 or visit the **John Tracy Clinic** on the web at www.johntracyclinic.org.

Hearing and Vision Connections (HVC)

is funded through the Illinois Department of Human Services, Bureau of Early Intervention. One of HVC's main goals is to provide families with information related to vision and hearing loss. HVC offers a variety of resources including a quarterly newsletter, vision kits, communication kits, sign language kits and this booklet. HVC is available to answer specific questions related to children with vision and hearing loss. They offer free statewide training. Contact Hearing and Vision Connections at 217/479-4318 (V/TTY). Visit them on the web at www.morgan.k12.il.us/isd/hvc.

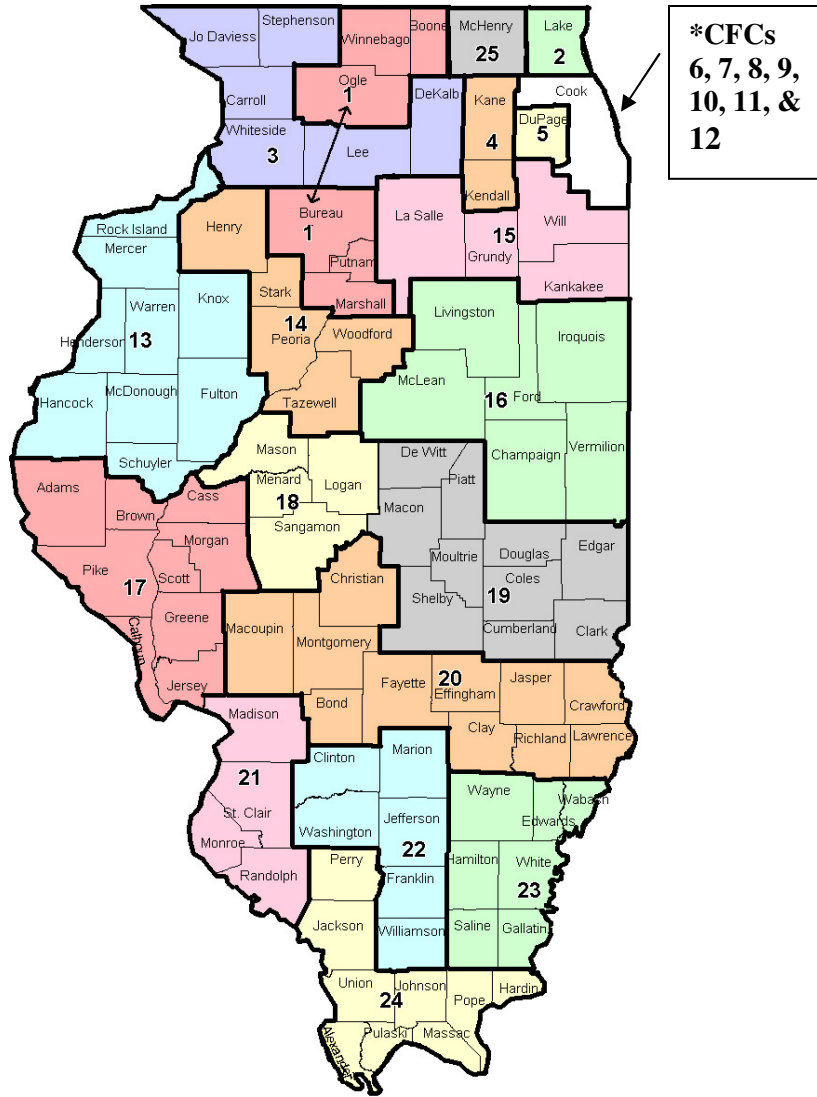


The **Illinois Early Childhood Intervention Clearinghouse** is a lending library. It is open to all Illinois residents. It has a vast array of books, periodicals, videos, and pamphlets related to vision and hearing loss and other topics. The Clearinghouse also has an informative newsletter that is mailed to families each month. Contact the clearinghouse for a free copy of their bibliography on blindness and visual impairment or on hearing loss. They will also help families find information on particular topics. Contact the clearinghouse at 800/852-4302. Visit them on the web at www.eicclearinghouse.org.



Child and Family Connections (CFC) Offices

Please call the Health and Human Services Help line at 800/ 843-6154 for contact information regarding your local CFC.



**Division of Specialized Care
for Children**

3135 Old Jacksonville Rd
Springfield, IL 62704-6488
Phone: 800-322-3722
Fax: 217-558-0773
www.uic.edu/hsc/dscc

Hadley School for the Blind

700 Elm Street
Winnetka, IL 60093 - 2554
Phone: 847/446 - 8111
800/323 - 4238
www.hadley-school.org

**Hearing and Vision
Connections**

125 Webster
Jacksonville, IL 62650
Phone: 217/479-4318 V/TTY
877/731-8184 V/TTY
www.morgan.k12.il.us/isd/hvc

**Illinois Advocates for the
Deaf-Blind**

818 DuPage Blvd.
Glen Ellyn, IL 60137
Phone: 630/790-2474
TTY: 800/771-1158
<http://project-reach-illinois.org>

Illinois School for the Deaf

125 Webster
Jacksonville, IL 62650
Phone: 217/479-4200 V/TTY
www.morgan.k12.il.us/isd

**Illinois Dept. of Human
Services**

Bureau of Early Intervention
222 South College, 2nd floor
Springfield, IL 62704
Phone: 217/782-1981
TDD/TTY: 217/558-6482
www.dhs.state.il.us/ei

**Illinois Parents of the Visually
Impaired**

PO Box 7477
Springfield, IL 62791
Phone: 877/411-IPVI (4784)
ipvi@ipvi.org
www.ipvi.org

**Illinois School for the Visually
Impaired**

658 East State Street
Jacksonville, IL 62650
Phone: 217/479-4400
800/919-5617
www.isvi.net

John Tracy Clinic

806 West Adams Blvd.
Los Angeles, CA 90007-2505
Phone: 213/748-5481
www.johntracyclinic.org

**National Family Assoc. for
Deaf-Blind**

141 Middle Neck Road
Sands Point, NY 11050
Phone: 800/255-0411
www.nfadb.org

To order additional copies of this free booklet
contact:

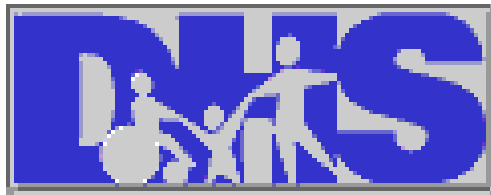
Hearing and Vision Connections

125 Webster St.
Jacksonville, IL 62650
217/479-4318 (V/TTY)
877/731-8184 (V/TTY)

Or download a copy from the web at:

www.morgan.k12.il.us/isd/hvc

Special thanks to the many agencies and
individuals that helped put this resource together.



State of Illinois
Department of Human Services
Bureau of Early Intervention