

Family Support

What does it mean?





Designated Service Coordinator Training

*Supporting Families who have children who are deaf, hard of
hearing, visually impaired, blind or deaf-blind*

Family Support and Partnership

Family support is an essential component of an effective EHDI system. EHDI coordinators and other stakeholders, such as the medical home and audiologists, have a responsibility to ensure:

- ▶ *Families are supported.* EHDI systems must ensure that families get access to culturally-competent information to help them make informed decisions. This also includes providing access family support groups to help provide emotional support as only other caregivers can offer.
- ▶ *Families are partners in decision making.* EHDI systems must honor family decisions about what is best for their own child and family. At a systems level, families with diverse perspectives can offer their expertise to guide EHDI practices and policies, resulting in more family-centered EHDI systems.

~retrieved from NCHAM website at <http://www.infanthearing.org/familysupport/index.html>

Parents Deserve....

- ▶ Respect
- ▶ Confidentiality
- ▶ Information and Support
- ▶ Decisions are theirs to make not yours. Be sure to recognize and keep your personal biases out of the picture.



Parents Often Want...

- ▶ Information about services available in the school district
- ▶ Information about accessible resources/events in the community
- ▶ Information about language, listening, speaking and how hearing impacts that
- ▶ Support in teaching their child to listen and communicate
- ▶ Support in managing their child's behavior
- ▶ Opportunities to meet other parents of children with hearing loss
- ▶ Information about parent support groups
- ▶ Opportunities to meet deaf/hard of hearing adults
- ▶ Ideas on communicating with other members of the team and managing time among therapies

Remember...



Siblings and extended family members
often need support and information too!

Sources of Information and Support for HEARING

- ▶ Audiologist
- ▶ DTH
- ▶ SLP
- ▶ EI team members
- ▶ Private therapists
- ▶ Physician/Pediatrician
- ▶ Deaf Mentors
- ▶ Parent Guides
- ▶ Local Deaf/Hearing Loss organization Coordinator
- ▶ Local education agency (local deaf education school program)

Resources

Communication

LISTENING AND SPOKEN LANGUAGE

- ▶ Alexander Graham Bell Association for the Deaf and Hard of Hearing
- ▶ www.listeningandspokenlanguage.org

AMERICAN SIGN LANGUAGE

- ▶ American Society for Deaf Children
- ▶ www.deafchildren.org

CUED SPEECH

- ▶ National Cued Speech Association
- ▶ www.cuedspeech.org

Resources

Online Materials

- Early Intervention: The Missing Link *video*
<http://aslized.org/journal/ei>
- Rachel Coleman from the Signing Time “One Deaf Child” *video*
<http://www.rachelcoleman.com>
- READ Kits
<http://www.choicesforparents.org>
- Cornerstone ???
- Nick News with Linda Ellerbee: Now Hear This! What If You Were Deaf? (video- will be posted on IDHHC website)
- Children and Hearing Loss Notebook: A Resource Manual for IL families
<http://www.choicesforparents.org>

- Some of the organizations host conferences/workshops providing training or have online trainings so be sure to check them out (and keep them on radar).
- The EI: The Missing Link video is a must watch by all in the EI profession.

Resources

Organizations & Programs

- Illinois School for the Deaf Outreach
- Deaf Mentoring Program
- Language Equality and Acquisition for Deaf Kids (LEAD-K)
- Choices for Parents
- Department of Human Services: Early Intervention
- Early Hearing Detection & Intervention Program (Sound Beginnings)
- Family Resource Center on Disabilities
- Parent Training & Information Center
- IL Hands & Voices, Guide By Your Side
- National Association for the Deaf
- Illinois Deaf and Hard of Hearing Commission

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Illinois School for the Deaf Outreach

<http://bit.ly/ISD-Outreach2>

Illinois School for the Deaf Evaluation Center

<http://illinoisdeaf.org/Services/Services.html>



Illinois Supervisors of Programs for Deaf and
Hard of Hearing Individuals

<http://www.ishi-il.org/>

National Parent Support Organization

Hands & Voices

www.handsandvoices.org

Illinois Hands & Voices, Guide By Your Side

www.ilhandsandvoices.org

FACEBOOK

[Illinois School for the Deaf Outreach](#)

[Illinois Hands & Voices](#)

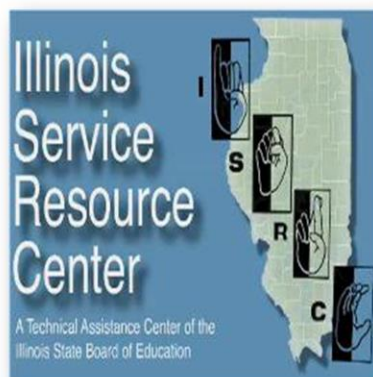
[Illinois Guide By Your Side](#)

[Illinois Service Resource Center](#)

[CHOICES for Parents](#)

State Support for Behavior and Lending Library

www.isrc.us



Deaf Mentor

- ▶ The Connections Program (CP) at Chicago Hearing Society (CHS) is an on-going, family-centered support program that links adults who are Deaf, DeafBlind or Hard of Hearing (D/DB/HH), called Mentors, with families who have children who are D/DB/HH, providing an array of support services.
- ▶ Through this connection, Mentors provide the entire family with the support, perspective, advocacy, community resources and options necessary for parents to help their D/DB/HH children achieve their full potential in both the hearing and deaf worlds.



Deaf Mentors are available to provide family support by sharing personal experiences, modeling language and communication strategies, linking to the local deaf community and providing insight on technologies for the deaf.

Sources of Information and Support for VISION

- ▶ Optometrist
- ▶ DTV
- ▶ DTO&M
- ▶ EI team members
- ▶ Private therapists
- ▶ Physician/Pediatrician
- ▶ Local Vision organization Coordinators
- ▶ Local education agency (local deaf education school program)

Resources

- ▶ <http://www.isvi.net>
- ▶ Service Guidelines
- ▶ DTV Brochure
- ▶ Project Reach brochure
- ▶ <http://www.philiprocenter.org/project-reach/technical-assistance>
- ▶ Supporting Families



Let's finish by discussing some resources that you should be aware of. These resources are available on the HVC website for your use. Some of them will be helpful for you. Others will be helpful resources for you to share with parents as they enter into the world of vision.

1. HVC Website: You visited this during our last break. Remember to take advantage of the tab created just for you entitled "Designated SC"
2. Vision Service Guidelines: This document contains most of the information that we have gone through today. These Service Guidelines are specific to children with vision loss.
3. DTV Brochure: This brochure will come in handy as you introduce the concept of a DTV to families. Help them to understand that a DTV is someone who will address the developmental needs of their child. This is different than the medical issues that their doctors will be addressing.
4. HVC Brochure: Again, this brochure will benefit the families you are serving. This is a means to introduce them to services within the vision world. Through us they will have the opportunity to learn about parent conferences, vision specific newsletter, training opportunities, etc.
5. Project Reach Brochure: This is important for families of children with any degree of vision and hearing loss, when they occur together. They present a unique set of challenges and the professionals at PRC are specially trained to help families address those needs.
6. Supporting Families: This is an all inclusive booklet for families. The Supporting Families booklet is an excellent item to leave with families. They can explore the contents at their leisure to learn about agencies or organizations to help meet their immediate needs.

Vision Resources

NEWSLETTERS, PICTURES, BLOGS

- ▶ WonderBaby
- ▶ <http://www.wonderbaby.org/>

ADVICE FROM FAMILIES

- ▶ Family Connect
- ▶ <http://www.familyconnect.org/info/browse-by-age/infants-and-toddlers/12>

VARIOUS EYE CONDITIONS

- ▶ American Foundation of the Blind Glossary of Eye Conditions
- ▶ <http://www.afb.org/section.aspx?SectionID=63&DocumentID=2139&rewrite=0>

FACEBOOK

Vision Parents Empowered of Chicagoland
Illinois Advocates for the Deaf-Blind (IADB)
Illinois Service Resource Center

National Parent Support Organizations

National Association of Parents of Children
with Visual Impairments (NAPVI)

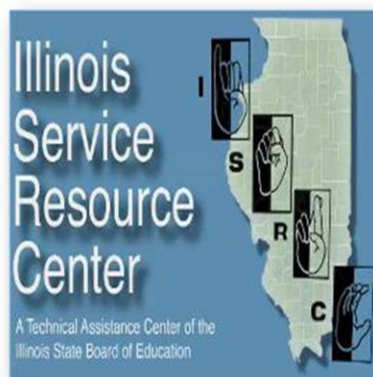
www.napvi.org

National Family Association for Deaf-Blind

<http://nfadb.org/>

State Support for Behavior and Lending Library

www.isrc.us



Illinois Vision Leadership Council

<https://sites.google.com/view/ivlc-vision-leadership-council>

<https://www.facebook.com/illioisvisionleadershipcouncil/>

▶ Support Contact:

▶ Andrea Marwah

▶ 708-409-8800

▶ Andrea.marwah@illinois.gov

▶ www.soundbeginnings.com



Website Link

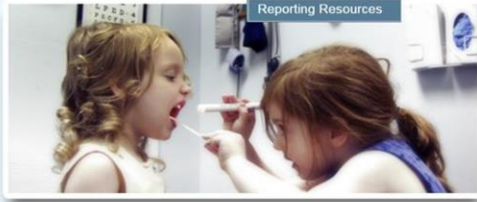
*This is where all your training materials
will be housed.*

<http://www.illinoissoundbeginnings.org/>

For Families | **For Providers** | For baby Facilities | Resources | Search

Detection & Intervention Program

- DSC Training
- Colic Medication (CMV)
- ECHO - OAE Hearing Screening
- EHDI News for Physicians
- EHDIPALS.org
- EHDI Workgroup Webinars
- Guide By Your Side (GBYS)
- Reporting Resources



UIC UNIVERSITY OF ILLINOIS AT CHICAGO

NEWS

[Learn American Sign Language \(9/21/2016\)](#)

[ECHO Initiative webinars \(7/6/2016\)](#)

[Introducing the Newest EHDI Physician Champion \(7/29/2015\)](#)

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Illinois EHDI works with parents and providers to ensure all babies get screened for hearing loss no later than 1 month of age; all infants who do not pass their hearing screen receive a diagnostic evaluation no later than 3 months of age; and all infants with a hearing loss enroll in early intervention services no later than 6 months of age.

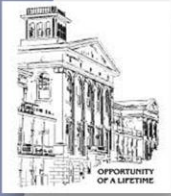
PROGRAM PARTNERS

UIC - Division of Specialized Care for Children
Tel: 800-322-3722 TTY 217-785-4725
Fax: 217-558-0773

Illinois Department of Public Health
Tel: 217-782-4733

Illinois Department of Human Services
Tel: 800-843-6154 TTY 800-447-6404





ILLINOIS SCHOOL FOR THE DEAF OUTREACH

FREE training and consultation for Illinois children
with hearing loss

bit.ly/ISDOutreach



Search for Illinois School for the Deaf Outreach



State of Illinois
Dept. of Human Services
Illinois School for the Deaf

Bruce Rauner, Governor
James Dimas, Secretary
Julee Nist, Superintendent