

babies & hearing loss



A Guide for Providers about
Follow-up Medical Care

Notes





DID YOU KNOW?

- *With the implementation of universal newborn hearing screening (UNHS) programs in the United States, the average age of identification of hearing loss has been significantly reduced from 30 months of age.¹*
- *Without appropriate opportunities to learn language, children who are hard of hearing or deaf will fall behind their hearing peers in language, cognition, and social-emotional development.²*

WHO SHOULD BE OFFERED AN AUDIOLOGY REFERRAL?

- All infants and children with risk factors identified by the Joint Committee on Infant Hearing that include medical, family history, and family or physician concern
- All infants who “refer” from hearing screening programs should be referred to an audiologist for determination of hearing levels

WHAT HAPPENS DURING AN AUDIOLOGIC EVALUATION?

Each individual infant presents unique characteristics that may influence the approach to the evaluation. The following are specific procedural recommendations (not standards) that are supported by research and clinical experience.^{3,4}

Birth to 36 months

[Note: the following should be included in all evaluations from birth to 36 months]

- Child and family history
- Otoscopic inspection
- Middle Ear Function: Acoustic emittance, bone conduction ABR, and/or pneumatic otoscopy. *[Note: tympanograms, physical volume, and acoustic reflexes should be assessed for both ears.]* The use of a probe frequency higher than 220/226 Hz should be considered.
- Parental report of emerging auditory behaviors
- Observation of Infant Behavioral Responses: Although reliable procedures for determining thresholds in this age population are not clinically available, this should not preclude observation in order to corroborate parent/caregiver report.

Birth to 6 months

[Note: appropriate referral shall be made for the following tests prior to diagnosis]

- Otoacoustic Emissions: Used to determine cochlear function at various frequencies.
- Auditory Brainstem Response (ABR): *[Note: use of an alternating click may eliminate the response needed to diagnose a possible auditory neuropathy.]* At a minimum, responses to clicks and low-frequency stimuli should be obtained to provide an estimate of audiometric configuration. When air-conducted ABR is elevated, a measure of middle ear function should be considered when equipment, normative data and expertise are available.

6 months to 36 months

- Behavioral Response Audiometry: Either visual reinforcement or conditioned play audiometry depending on the child’s developmental age (including speech detection and recognition measures when appropriate).

- Otoacoustic Emissions: Used to determine cochlear function at various frequencies.
- Auditory Brainstem Response (ABR): Recommended use is to confirm questionable behavioral responses. [Note: use of an alternating click may eliminate the response needed to diagnose a possible auditory neuropathy.] At a minimum, responses to clicks and low-frequency stimuli should be obtained to provide an estimate of audiometric configuration. When air-conducted ABR is elevated, a measure of middle ear function should be considered when equipment, normative data and expertise are available.

At the conclusion of the evaluation, the audiologist will:

- Provide the family with information about the infant's hearing acuity
- Discuss recommendations for additional assessments by other specialists
- Refer the infant and family to the local Birth to 3 Program
- Explain the potential implications of any hearing loss to the caregivers
- Send a copy of the Audiology Confirmation of Hearing Loss Report to the infant's primary care physician, otolaryngologist, and family

WHAT ARE THE ROLES OF THE AUDIOLOGIST FOLLOWING DIAGNOSIS?

The audiologist will:

- Provide timely fitting and monitoring of amplification (sensory devices and assistive technology with family consent)
- Provide family education, counseling, and ongoing participation in the development and implementation of the infant's individualized family service plan (IFSP). In addition, the audiologist may provide direct auditory habilitation services to the infant and families.
- Participate in an assessment of the candidacy for cochlear implantation
- Collaborate and communicate with other providers within the UNHS continuum of care including the child's primary care physician

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3. Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. Joint Committee of Infant Hearing, American Academy of Audiology, American Academy of Pediatrics, American Speech-Language-Hearing Association, and Directors of Speech and Hearing Programs in State Health and Welfare Agencies. *Pediatrics, (2000)*. Oct; 106(4): 798-817.
4. Guidelines for the audiologic assessment of children from birth through 36 months of age. Committee on Infant Hearing American Speech-Language-Hearing Association (1991). *ASHA Suppl.5*, 37-43.



DID YOU KNOW?

- *At least 50% of congenital-early onset, severe-profound hearing loss has a genetic cause.*
- *Most genetic hearing loss is isolated; however, complex syndromes with other associated medical problems or birth defects do affect one-third of individuals with hearing loss.*
- *In some instances, identification of associated features in hearing loss syndromes may have health saving or life saving implications.*
- *Since the majority of genetic hearing loss is caused by recessive (hidden) genes, the infant's family history is usually negative for hearing loss.*

WHO SHOULD BE OFFERED A REFERRAL?

A referral for genetic evaluation is an important part of the diagnostic work-up for infants and their families who are identified with hearing loss through the newborn hearing screening program. Guidelines for referring an infant with hearing loss for a genetic evaluation include:

- All children with bilateral moderate, severe or profound sensorineural hearing loss
- A child with any degree of hearing loss (including unilateral or mild) who also has either a family history of hearing loss or other co-existing medical problems or birth defects
- Families who are interested in learning more about the possible genetic causes for their infant's hearing loss

WHY IS GENETICS IMPORTANT TO HEARING LOSS?

Epidemiologic studies have shown that at least 50-60% of early onset severe-profound hearing loss is genetic. In addition, genetic types of hearing loss may also be associated with mild-moderate, unilateral or progressive hearing loss, particularly when there is a family history of hearing loss or if a child has other co-existing medical problems or birth defects. Over 400 different types of genetic hearing loss have been described. Several genes have been cloned allowing for DNA testing for a number of genetic types of hearing loss. The most common type of isolated recessive hearing loss is associated with mutations in the Connexin 26 gene¹.

The majority of individuals with a genetic hearing loss are otherwise healthy with no other associated medical problems or birth defects. However, one-third of people with hearing loss will have associated medical problems, such as cardiac, eye, renal, metabolic, musculoskeletal, neurologic or other disorders as part of a complex syndrome. Often, identification of these associated features has significant implications for the health and medical management of the child.

Recurrence risks for future children with hearing loss may also be determined through genetic evaluation. These risks are dependent on the etiology of the identified hearing loss. This etiology may be determined by a genetic physical examination, family and medical history review, laboratory tests or other medical evaluations.

WHAT HAPPENS IN A GENETIC EVALUATION?

The identification of the cause of hearing loss through a genetic evaluation is essential to providing the infant with appropriate medical and educational management, as well as

providing the family with accurate information about the cause, recurrence risks for future children and implications for other family members. Typically, a child and his/her family will see a clinical geneticist and genetic counselor during the evaluation.

Genetic assessment usually includes:

- Obtaining at least a three generation family pedigree
- Review of pregnancy, medical and exposure histories
- A physical examination by a clinical geneticist
- Audiologic evaluation of parents, and when indicated, of siblings and other family members

Other studies may be indicated depending upon the results of these initial evaluations, including:

- Chromosome analysis and DNA testing for Connexin 26 or other genetic mutations
- Metabolic testing
- Computerized tomography of temporal bones
- Ophthalmologic examination including electroretinography
- Cardiac evaluation including an electrocardiogram
- Renal evaluation

Smith et al.² provide an overview of some syndromic causes of hearing loss and the benefit of the medical genetic evaluation.

At the conclusion of the genetic evaluation, information about the cause of the child's hearing loss, and any associated physical, medical or developmental features will be discussed. Recommendations for additional assessment and ongoing care will be provided. The implications of this information for future children, and other family members will also be addressed. In addition, the geneticist/genetic counselor can often provide families with resource materials, and parent-parent networks for more information and support. Depending on the cause of the child's hearing loss, some families may only see the geneticist/genetic counselor for a single consultation, while for other children longer term genetic follow-up may be indicated.

Referring physicians may find that some families may be hesitant about a referral for genetic evaluation or have misinformation or misconceptions about genetic services. However, a recent study found that the majority of hearing parents do feel that genetic testing would be beneficial³. Referring physicians should reassure parents that geneticists and genetic counselors are specifically trained to understand the impact that a genetic diagnosis has on a family. Issues related to the psychosocial impact of a diagnosis, and other concerns the family has (such as genetic discrimination or privacy) will be addressed in genetic counseling. Genetic counseling should always precede genetic testing so that families can make informed decisions and learn about the possible benefits, risks and limitations of such testing.

For more information about a genetic referral for your patients with hearing loss or to obtain a list of genetics centers in your area contact the State of Wisconsin Genetics Coordinator at (608) 267-7148.

SUGGESTED REFERENCES:

1. Cohn, E.S., Kelley, P.M. (1999). Clinical phenotype and mutations in connexin 26 (DFNB1/GJB2), the most common cause of childhood hearing loss. *Am J Med Genet*, 89,130-136.
2. Smith, S.D., Kimberling, W.J., Schaefer, G.B., Horton, M.B., & Tinley, S.T. (1998). Medical genetic evaluation for the etiology of hearing loss in children. *J Commun Disord* 31, 371-389.
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DID YOU KNOW?

- *Hearing screening programs allow for earlier identification of hearing loss in infants. This has led to changes in how infants are evaluated and managed. It has also led to improvements in speech, language, and developmental outcomes for the child.*
- *Even mild or unilateral hearing loss may have a significant impact on an infant's social, language and cognitive development, and should be fully evaluated by an otolaryngologist.*
- *Hearing research continues to make significant advances, and the means of habilitating infants with hearing loss are continuously being improved.*
- *Some forms of hearing loss in infants are completely reversible with appropriate intervention.*

WHO SHOULD BE OFFERED A REFERRAL?

All infants with confirmed hearing loss should be referred to an otolaryngologist.

WHAT WILL OCCUR DURING THE ENT EVALUATION?

The otolaryngologist's history will focus on possible factors associated with the infant's hearing loss including:

- Intrauterine and perinatal risk factors
- Exposure to ototoxic medications
- Family history
- Association with syndromic causes of hearing loss

Some of the most useful tools for establishing a potential cause of sensorineural hearing loss are thorough history taking and documentation. Pappas and Schaibly¹ suggested that family and medical histories as well as a complete physical examination are essential in early pediatric surveillance for hearing loss.

The otolaryngologist will perform a complete head and neck examination and microscopic ear examination to identify factors associated with the infant's hearing loss including:

- Possible structural or anatomic abnormalities
- Dysmorphic or syndromic features known to be associated with hearing loss
- Presence of fluid in the middle ear

If fluid is the cause of the infant's hearing loss it may be reversible with surgical intervention. Other conditions may be reversible with surgical intervention later in life and early identification may help plan for surgical rehabilitation.

WHAT ADDITIONAL TESTS MAY BE ORDERED BY AN ENT?

The otolaryngologist will help direct further diagnostic evaluation of the infant identified with hearing loss, through a collaborative relationship with the audiologist and primary care provider. Using current technology they will identify the degree and severity of the infant's hearing loss. Current methods allow for a very accurate diagnosis of the nature and severity of hearing loss in children of any age. For some infants, the otolaryngologist and audiologist may have to work together to provide appropriate levels of sedation to allow the audiologist to obtain the most accurate information regarding the infant's level of hearing. This information is extremely important, as it will determine the type of intervention required to achieve habilitation.

There is variation in the literature and in general practice regarding the “best practice” in the diagnostic evaluation of an infant newly identified with hearing loss. The standard evaluation is in flux due to some promising new genetic tests that are able to identify the cause of congenital hearing loss (such as testing for changes in the gene coding for connexin 26, which may account for approximately 50% of infants with congenital non-syndromic hearing loss). Because of the complexity of the new genetic discoveries in hearing loss, the otolaryngologist may recommend referral for genetic assessment, counseling and testing.

Other tests are often ordered to identify a specific cause of the hearing loss or to identify conditions associated with syndromic hearing loss. The tests that have the greatest utility are those that may affect the management or the possibility of progression in the child’s hearing loss. Most otolaryngologists obtain a high-resolution CT scan of the temporal bones to identify conditions such as Mondini malformation or a large vestibular aqueduct. These conditions have significant medical implications and associations with progression in hearing loss that may be prevented with appropriate counseling and intervention.

With earlier diagnosis of infant hearing loss, Cytomegalovirus (CMV) titer testing has become important. If administered in the first month of life, gancyclovir has been shown to lessen the progression of hearing loss in infants.

Findings in the history or physical exam may indicate an association with the infant’s hearing loss and other medical conditions. Other tests that may be ordered to investigate this association or to investigate a specific syndrome associated with the hearing loss include:

- Renal function testing
- Cardiac evaluation and electrocardiogram
- Ophthalmology consultation and electroretinography
- Evaluation for endocrine function (thyroid, pancreatic)
- Fluorescent treponemal antibody testing
- Autoimmune evaluation
- Evaluation for anemia

WHAT ABOUT MILD OR UNILATERAL HEARING LOSS?

Numerous studies have demonstrated that simply monitoring children with mild or unilateral hearing loss is not the best approach. As with infants with bilateral hearing loss, these infants with unilateral loss require a thorough audiologic evaluation as well as an evaluation by an otolaryngologist. Even mild unilateral hearing loss may contribute to difficulties in social and emotional function, educational achievement and communication in some children.

Given the prevalence of otitis media in infants and young children, complete evaluation and close follow-up is essential. A unilateral loss may be caused by a reversible condition (such as middle ear fluid caused by otitis media) that can be diagnosed and treated by the otolaryngologist. The persistence of middle ear fluid in an infant makes it difficult for an infant to develop speech and language skills.

WHAT ABOUT HABILITATION IN INFANTS WITH HEARING LOSS?

The team of audiologists, speech and language pathologists, deaf educators, and other specialists such as Birth to 3 Program early interventionists, will be involved in habilitating infants with hearing loss. However, the otolaryngologist also plays an important role through

- Routine evaluation of the ears
- Reassessment of the infant’s ears when there are hearing aid difficulties
- Assessment of cerumen accumulation or related issues
- Close monitoring and treatment of difficulties arising from otitis media

In some children with profound hearing loss, habilitation through the use of a cochlear implant may be an option. An otolaryngologist with specific training in cochlear implantation will help determine if this intervention is appropriate for the infant and family, and is able to perform the surgical procedure required for this device.

REFERENCES:

1. Pappas, D.G., & Schaibly, M. (1984). A two-year diagnostic report on bilateral sensori-neural hearing loss in infants and children. *American Journal of Otolaryngology*, 5, 339-343.



DID YOU KNOW?

- *Infants who are hard of hearing or deaf who receive intervention before 6 months of age maintain language development commensurate with their cognitive abilities through the age of 5 years.*
- *Medicaid certified providers must refer all deaf or hard of hearing infants to the designated county Birth to 3 Program agency within two working days of identification.*

The Birth to 3 Program is Wisconsin's early intervention program for infants and toddlers with developmental delays and disabilities and their families. The Birth to 3 Program is:

- *Based on the Individuals with Disabilities Education Act (IDEA), Part C, which provides rules for early intervention programs in all states. IDEA provides that the Birth to 3 Program must be an entitlement for eligible infants and children. The Birth to 3 Program must provide the services and supports a child needs.*
- *Administered by the Department of Health and Family Services (DHFS) and has regulations in State Administrative Code, Reference Number HFS 90. Each county is responsible for coordinating and arranging for the actual provision of early intervention services according to state and federal regulations.*

WHO SHOULD BE OFFERED A REFERRAL TO THE BIRTH TO 3 PROGRAM?

Any infant with a hearing loss whose diagnosis has been confirmed by an audiologist, regardless of type, configuration, or degree of loss, should be referred to the local Birth to 3 Program.

WHO MAY REFER A CHILD WITH HEARING LOSS TO THE BIRTH TO 3 PROGRAM?

- Parents
- Pediatricians
- Family practice physicians
- Audiologists
- Speech language pathologists
- Public Health Nurses
- Otolaryngologists

In other words, anyone who suspects that the child is at risk for delay as a result of the hearing loss or other developmental issues can make the referral. However, for health care providers, the Code of Federal Regulations (CFR) 34 Part 303 requires Medicaid health care providers to identify children with developmental delays, atypical development, and disabilities who might be eligible for Birth to 3 Program services. Providers are encouraged to explain the need for the Birth to 3 Program referral to the infant's parent(s)/guardian(s), however consent for referral is not required. Parents or providers may call 1-800-642-STEP to find the number of their local Birth to 3 Program to make a referral.

HOW ARE CHILDREN FOUND ELIGIBLE?

Children ages birth to 36 months are evaluated for eligibility by an early intervention team that includes at least two professionals from different disciplines. In general, eligibility for Birth to 3 Program services is based on the presence of one of the following:

- A diagnosed condition known to have a high probability of resulting in a developmental delay
- A 25% or greater delay in at least one of five areas (cognition, physical/motor development, speech and language development, social and emotional development, self-help/adaptive development)
- Atypical development

Studies have indicated that without early identification and intervention services, an infant's hearing loss is likely to result in a developmental delay. These studies have also concluded that if intervention services are not administered until after the delay is apparent, the beneficial effects of early identification will be minimized. Therefore, Wisconsin has determined that a child with a hearing loss does not need to demonstrate a developmental delay to be eligible for the Birth to 3 Program.

The regulations for the Birth to 3 Program do not base eligibility on specific types or degree of hearing loss. There is not a required decibel loss nor are children with unilateral hearing loss excluded. Providers should refer any child diagnosed with a hearing loss under the age of 36 months to the Birth to 3 Program.

If the early intervention team determines that the child's hearing loss is not predicted to result in developmental delay, they must offer to reconsider the child's eligibility within six months. The early intervention team should also provide information about, and offer to refer the family to, community services that may benefit the infant and family.

WHAT SERVICES WILL A FAMILY WITH A DEAF OR HARD OF HEARING CHILD RECEIVE?

- A service coordinator and other early intervention staff will meet with the family as a team to determine:
 - ✓ The child's developmental strengths and needs
 - ✓ The family's priorities and concerns
 - ✓ Resources and support networks
- Assistance in creating an Individual Family Service Plan (IFSP) which may include services and supports such as:
 - ✓ Communication services and supports
 - ✓ Family education
 - ✓ Developmental education services
 - ✓ Related health services
 - ✓ Occupational therapy
 - ✓ Physical therapy
- The service coordinator works with the family to see that the family and infant receive the services and supports they need within a family's natural environment. A natural environment is a place where the family would typically spend time if their child did not have a delay, such as the family home, childcare, or other community setting.
- HFS 90 also states that:
 - ✓ Service coordination in the Birth to 3 Program includes coordinating with an infant's medical and other health care providers.
 - ✓ That an infant's IFSP shall contain, if appropriate, medical and other services that the infant needs, that are not required under the Birth to 3 Program and that steps will be taken to secure those services from other public or private sources. *This does not apply to routine medical services such as immunizations and well baby care unless an infant needs those services and they are not otherwise available or being provided.*

HOW IS THE BIRTH TO 3 PROGRAM FUNDED?

The Birth to 3 Program is financed by a combination of federal, state, and county funds. Additionally, county programs and their providers pursue outside funding from third party payers, and private donations. Families are asked to contribute through a cost share based on their income.

HOW DOES THE BIRTH TO 3 PROGRAM AFFECT YOU?

Many physicians and other health care professionals provide services to children enrolled in the Birth to 3 Program. You have the potential to impact the overall development and well being of children diagnosed with hearing loss by referring them to the local Birth to 3 Program. If you are interested in more information regarding the impact of the Birth to 3 Program on children with hearing loss and their families, please contact Jean Nothnagel, Birth to 3 Health Policy Coordinator, at (608) 266-5442 or nothnjl@dhfs.state.wi.us.



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The information contained within this section is an overview of professional services involved in the diagnosis and management of infants with hearing loss and their families. These resources may provide you or the families you are in contact with additional information about hearing loss, professional services, or parent-to-parent support groups. If a resource has only a TTY number listed, please contact the Wisconsin Relay System at 711.

STATE AND LOCAL ORGANIZATIONS

Office for the Deaf and Hard of Hearing (BDHH)

Central Administration Office
PO Box 7851
1 W. Wilson St., Room 451
Madison, WI 53707-7851
(608) 266-3118 Voice/TTY
(608) 264-9899 Fax
Linda Huffer
Internet: www.dhfs.state.wi.us/sensory

Center for the Deaf and Hard of Hearing (CDHH)

3505 N. 124th Street
Brookfield, WI 53005
(262) 790-1040 Voice
(262) 790-0584 TTY
(262) 790-0580 Fax
Dorothy Kerr, Executive Director

Cochlear Implant Club of Wisconsin

119 Oconomowoc Square
Oconomowoc, WI 53066
(262) 267-9621 Voice (work)
(262) 832-6332 (home)
Carol Burns, President
Work e-mail: burnsca@dwd.state.wi.us
Home e-mail: burnsca@chorus.net

Wisconsin Association of the Deaf (WAD)

111 W. Wilson, #302
Madison, WI 53703
(608) 250-6076
Linda Russell, President
E-mail: linda_russell@sbcglobal.net
russelm@dhfs.state.wi.us
Internet: www.wi-deaf.org

Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESPDHH)

Alex Slappey, Director
309 W. Walworth Avenue
Delevan, WI 53115
(262)740-2066 v/tty
E-mail: alex.slappey@dpi.state.wi.us

Wisconsin School for the Deaf

309 W. Walworth Avenue
Delevan, WI 53115
Internet: www.wsd.k12.wi.us/

Outreach Program-WESPDHH

Marcy Dropkin, Outreach Director
19601 W. Bluemound Road
Brookfield, WI 53045
(262)787-9540 v/tty
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Deaf Mentor Project

WESPDHH-Outreach Program

Marika Kovacs-Houlihan, Project Co-Coordinator
Bonnie Eldred, Project Co-Coordinator
E-mail: deafmentor@wesp-dhh.wi.gov

Wisconsin Relay System

Western Tower Building
8383 Greenway Blvd., Suite 90
Middleton, WI 53562
(800) 283-9877 TTY
(800) 395-9877 Voice, VCO
(608) 827-0402 Fax
E-mail: wirelay@hamilton.net
Internet: www.hamilton.net/relay/wi

NATIONAL ORGANIZATIONS***Alexander Graham Bell Association for the Deaf and Hard of Hearing (AGBell)***

3417 Volta Place NW
 Washington, DC 20007
 (202) 337-5220 Voice
 (202) 337-5221 TTY
 (202) 337-8314 Fax
 Internet: www.agbell.org

American Academy of Audiology (AAA)

8300 Greensboro Dr., Suite 750,
 McLean, Virginia 22102
 (800) AAA-2336 Toll-Free
 (703) 790-8466 Voice
 (703) 790-8631 Fax
 Internet: www.audiology.org

American Society for Deaf Children

P.O. Box 3355
 Gettysburg, PA 17325
 (717) 334-7922 Business V/TTY
 (717) 334-8808 Fax
 (800) 942-ASDC Parent Hotline
E-mail: asdc@deafchildren.org
 Internet: www.deafchildren.org

American Speech-Language-Hearing Association (ASHA)

EXEC. DIRECTOR: Frederick T. Spahr, Ph.D.
 10801 Rockville Pike
 Rockville, MD 20852
 Helpline: (800) 498-2071 (Voice/TTY)
 (301) 897-5700 TTY
 (301) 571-0457 Fax
 John E. Bernthal, President
E-mail: actioncenter@asha.org
 Internet: www.asha.org

Cochlear Implant Association, Inc.

5335 Wisconsin Avenue, NW, Suite 440
 Washington, DC 20015-2052
 (202) 895-2781
 (202) 895-2782 Fax
 Internet: www.cici.org

Families For Hands and Voices

P.O. Box 371926
 Denver, CO 80237
 (303) 300-9763
 (866) 422-0422 Toll Free
 Internet: www.handsandvoices.org

National Association of the Deaf (NAD)

814 Thayer Avenue
 Silver Spring, MD 20910-4500
 (301) 587-1788 Voice
 (301) 587-1789 TTY
 (301) 587-1791 Fax
E-mail: NADinfo@nad.org
 Internet: www.nad.org

National Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492
 Washington, DC 20013
 (800) 695-0285 V/TTY
 (202) 884-8200 V/TTY
 (202) 884-8441 Fax
E-Mail: nichy@aed.org
 Internet: www.nichcy.org

National Institute on Deafness and Other Communication Disorders

National Institutes of Health
 31 Center Drive, MSC 2320
 Bethesda, MD USA 20892-2320
 Internet: www.nidcd.nih.gov

Laurent Clerc National Deaf Education Center and Clearinghouse at Gallaudet University

800 Florida Ave. NE
 Washington, DC 20002
 Kendall Demonstration Elementary School
 Internet: www.clerccenter.gallaudet.edu/InfoToGo

Self Help for Hard of Hearing People, Inc. (SHHH)

National Chapter
 7910 Woodmont Ave-Suite 1200
 Bethesda, Maryland 20814
 (301) 657-2248 Voice
 (301) 657-2249 TTY
 (301) 913-9413 Fax
E-mail: National@shhh.org
 Internet: www.shhh.org



***Internet links providing information for families of deaf or hard of hearing children
and the professionals who work with them.***

RESOURCE INFORMATION URL

Americans with Disabilities Act information	www.usdoj.gov
American Sign Language Dictionary Online	www.feist.com
Centers for Disease Control and Prevention	www.cdc.gov/ncbddd/ehdi
Cultural access program	www.signlanguage.com
Deaf culture resources	www.wacky.ccit.arizona.edu
Deafness Resources	www.deafnation.com
Gallaudet University-info. about deaf/hard of hearing	clercenter.gallaudet.edu/infotogo
Handspeak sign language dictionary	www.handspeak.com
Hearing Health Magazine	www.hearinghealthmag.com
House Ear Institute	www.hei.org
Gallaudet Library	www.library.gallaudet.edu
Listen-up advocacy and discussion site for parents of deaf or hard of hearing children	www.listen-up.org
John Tracey Clinic	www.jtc.org
Parent Advocacy Coalition for Educational Rights	www.pacer.org
Nat'l Technical Institute for the Deaf	www.rit.edu/NTID
Publication-DEAFDIGEST by Barry Strassler	www.yellowstar.com

ACCESSIBILITY/EQUIPMENT URL

Abledata Assistive Technology	www.abledata.com
Captioned films and videos free loan program	www.cfv.org
Caption Center	main.wgbh.org/wgbh/pages/captioncenter
Closed captioning web site	www.erols.com/berke
Nat'l Center for Accessible Media	www.wgbh.org/ncam
Service dog information	www.grunt.berkeley.edu/ci
Hear More	www.hear.com
Hitec Group International	www.hitec.com
Med-El	www.medel.com/index.htm
Sign Enhancers Inc.	www.teleport.com/~sign
Soundbytes	www.soundbytes.com
Ultratec	www.ultratec.com
Universalink	www.execpc.com.cdhh



How Do I Get More Information?

The following is a list of resources that may be helpful for families:

Wisconsin First Step Hotline

www.mch-hotlines.org

(800) 642-7837 voice/TTY

Callers get information on a full range of services and programs for children with special needs, birth to 21. They can provide connection to parent-to-parent networks. This hotline is available 24 hours a day, 365 days of the year.

Wisconsin Office for the Deaf and Hard of Hearing

www.dhfs.state.wi.us/sensory

(608) 266-3118 voice/TTY

The Office for the Deaf and Hard of Hearing is located within the Division of Disability and Elder Services within the Department of Health and Family Services and has six regional offices that provide educational and referral services. They can connect individuals with other parents of deaf and hard of hearing infants as well as other state agencies to assist families with specific needs.

National Center for Hearing Assessment and Management (NCHAM)

www.infanthearing.org

This site contains a wealth of information on resources for families and professionals. It has links to family support groups such as the American Society for Deaf Children, AG Bell, Family Voices, and Family Village and professional groups such as the American Academy of Pediatrics and the American Speech Hearing and Language Association.

**Wisconsin Department of Health & Family Services, Division of Public Health
Bureau of Family and Community Health • Program for Children with Special Health Care Needs**

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