# GUIDELINES FOR NEWBORN HEARING SERVICES

MARCH 19, 2002

(Revision May 1, 2003)

# Dear Provider:

Enclosed is the 2003 printing of the Guidelines for Newborn Hearing Services for the Michigan's Early Hearing Detection and Intervention System. The purpose of the guidelines is to provide direction and consistency in the standard of care for Michigan's newborns. The development of the guidelines began in the fall of 2000 with the help of The Michigan Association for Deaf, Hearing, and Speech Services (MADHS) and the Michigan Department of Community Health, Early Hearing Detection and Intervention (MDCH/EHDI) Program. Countless hours were spent in committees developing the guidelines. Committees included consumers, professionals in related hearing fields, educators, organizations, audiologists, physicians, and parents. Since the first publishing in 2002, over 1,000 guidelines have been distributed throughout Michigan. Michigan has also been recognized nationally through the Centers for Disease Control and Prevention for their Genetic Evaluation Guidelines, which have been requested by other state EHDI Programs.

Every year in the month of December, the guidelines will be open for public comment. Comments should be submitted in writing to MADHS, Early Identification Subcommittee. Comments for 2002 included:

• Tertiary care facilities

• Financial information

- Monitoring of amplification
- Qualifications of audiologists 
  Eligibility for early intervention services
  - Joint Committee on Infant Hearing risk Indicators
    - Title change to diagnostic audiologic evaluation
- Definition of hearing loss

The guidelines will again be open for public comment in December of 2003. You are welcome to order the guidelines or copy selected guidelines as may be needed. Copies can be obtained by calling the MADHS at (517) 487-0066 or the MDCH/EHDI Program at (517) 335-9560.

Michigan's Early Hearing Detection and Intervention System continues to grow since its beginning in 1997. The goals of the program are 1) to have all Michigan newborns receive a hearing screen by one month of age, 2) for newborns who do not pass the hearing screen to have hearing outcomes by three months of age, and 3) for infants identified with hearing loss to have early intervention services initiated by six months of age. Michigan should be very proud of their progress on these goals. As of the end of 2002:

- 101/102 birthing hospitals have universal newborn hearing screening programs
- 93% of newborns had a hearing screen completed
- Since 1998, 726 infants have been identified with hearing loss with the average age of identification decreased from 25months (1997) to 6 months (2002)
- Documented enrollment in *Early On* ® Michigan has increased to 72%.

# We have come along way but, we still have work to do.

Michigan's Early Hearing Detection and Intervention System is a voluntary system, relying on Michigan's efforts in reporting (i.e., hearing screen, diagnostic and early intervention outcomes) to the MDCH/EHDI Program and the continual collaboration with hospitals, Medical Homes, audiologists, early interventionists, educators, local health departments, advocates, parent(s)/caregiver(s) and others with interest in the early hearing detection and intervention.

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#### **Statewide Review Process**

Special thanks to individuals and agencies who provided comments as part of the statewide review process.

# Table of Contents

	<u>Page</u>
Guidelines for the Medical Home	1
Normal Hearing Screen	1
Missed Hearing Screen	2
Infant Born Outside of Hospital	2 2
Abnormal Inpatient Hearing Screen	2
Abnormal Outpatient Hearing Screen	3
Confirmed Hearing Loss	3
References and Resources	6
Attachment A: Flow Chart	7
Attachment B: JCIH Risk Indicators	8
Guidelines for Hearing Screening	9
Protocol for Initial Hearing Screen	9
Protocol for Hearing Rescreen	11
Reporting Process	12
Program Management	12
Screener Proficiency and Evaluation	13
Hearing Screening Criteria	13
Quality Indicator	14
References and Resources	15
Attachment A: Flow Chart	16
Guidelines for Diagnostic Audiologic Evaluation	17
Assessment Site Requirements	17
Diagnostic Audiologic Evaluation Battery	17
Results	18
Hearing Aid Option	20
Suggested Audiologic Follow-up and Medical Management	23
Personnel Requirements	23
References and Resources	24
Guidelines for Genetic Evaluation Referral	26
Purpose of Referral	26
When to Make a Referral	26
Responsibilities or the Referral Process	28
Where to Make the Genetic Referral	29
Genetic Evaluation	29
References and Resources	31
Attachment A: Websites Resources	32
Attachment B: Genetic Clinic Contact Information	33
Guidelines for Early Intervention	34
Early Intervention Process	34
Principles of Effective Early Intervention	35
Quality Indicators for Early Intervention Programs	41
Monitoring System for Michigan	42
References and Resources	43
Attachment A: Early On Michigan Referral Process	45
Attachment B: Standards for Early Intervention Service Providers	46
Attachment C: Eligibility for Early On and Special Education Services	52

MADHS-COALITION FOR DEAF AND HARD-OF-HEARING PEOPLE, EARLY IDENTIFICATION SUBCOMITTEE 2929 COVINGTON COURT SUITE 200, LANSING MI• 48912-4939

# **GUIDELINES FOR MEDICAL HOME**

The American Academy of Pediatrics believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a relationship of mutual responsibility and trust with them. These characteristics define the "Medical Home" and describe the care that has traditionally been provided by pediatricians in an office setting (AAP, 1992).

The Medical Home should ensure that all newborns receive a hearing screen before ONE MONTH OF AGE. If the result of the hearing screen is unknown, the Medical Home should contact the birthing hospital's newborn hearing screening program to determine the hearing screen result. For those newborns who do not pass the birth-admission hearing screen, the Medical Home should ensure that a complete diagnostic outcome is obtained before the infant is THREE MONTHS OF AGE. If a hearing loss is identified, the Medical Home should ensure that early intervention services are initiated before the infant is SIX MONTHS OF AGE. It is the medical home's responsibility to monitor infants and young children for risk indicators for hearing loss (see Attachment A: JCIH Risk Indicators).

Costs of hearing screening, rescreening and/or diagnostic services may be covered by third-party insurers, Medicaid, Early On, MI-Child, and/or Children's Special Health Care Services.

- I. NORMAL HEARING SCREEN (pass result in both ears after a hearing screen or rescreen)
  - A. <u>Screening Hospital's Responsibilities:</u>
    - 1. Provide results to the infant's family.
    - 2. Provide written information to the infant's family regarding acquired, delayed onset, and progressive hearing loss.
    - 3. Provide the infant's family with a copy of the *Michigan's Community Hearing Screening Program: Information for Parents* (MDCH-0474 7/01). Copies can be ordered, free of charge, from the Michigan Department of Community Health, Early Hearing Detection and Intervention (MDCH/EHDI) Program at (517) 335-9560.
    - 4. Provide results to the Medical Home.
    - 5. Report results to the MDCH/EHDI Program (FAX: (517) 335-8036).
  - B. <u>Medical Home's Responsibilities:</u>
    - 1. Monitor ongoing development of communication skills, as well as risk indicators for acquired, delayed onset and progressive hearing loss (see Attachment A: JCIH Risk Indicators).
    - 2. Provide referrals to a pediatric audiologist and other medical specialists for parental/caregiver concerns and/or suspected delays. A pediatric audiologist has the competence, extensive experience and equipment

needed to evaluate the hearing acuity of newborns, infants, and young children (See Guidelines for Diagnostic Audiologic Evaluation).

- 3. For infants who pass the newborn hearing screen but who have risk indicators associated with late-onset, progressive, or fluctuating hearing loss, the Medical Home should ensure that the infant receives ongoing audiologic and medical surveillance and monitoring for communication development (JCIH, 2000).
- II. MISSED HEARING SCREEN (or hearing screen not completed before discharge)
  - A. <u>Screening Hospital's Responsibilities:</u>
    - 1. Hospital personnel will retain initial responsibility for recall and hearing screen.
    - 2. Provide written notification to the infant's family.
    - 3. Provide written notification to the Medical Home if infant does not return for the hearing screen after one month.
  - B. <u>Medical Home's Responsibilities:</u>
    - 1. Ensure and coordinate the hearing screen with the family by one month of age or one month after discharge from the NICU.
    - 2. Aid screening hospital with recall efforts, if needed.

# III. INFANT BORN OUTSIDE OF HOSPITAL

- A. <u>Medical Home's Responsibilities:</u>
  - 1. Provide the family with the name, address, and telephone number of the local birthing hospital or audiologic site that provides newborn hearing screening services.
  - 2. Counsel the family regarding the importance of having a hearing screen completed as soon as possible or by one month of age.
- IV. ABNORMAL INPATIENT HEARING SCREEN (in one or both ears before discharge) A. <u>Screening Hospital's Responsibilities:</u>
  - 1. Provide and explain written results to the family before discharge.
  - 2. Report results to the infant's Medical Home.
  - 3. When possible, an outpatient hearing rescreen should be scheduled before discharge.
  - 4. Report results to the MDCH/EHDI Program (FAX: (517) 335-8036).
  - 5. Provide the family with a copy of the *Michigan's Community Hearing Screening Program: Information for Parents* (MDCH-0474 7/01). Copies can be ordered, free of charge, from the MDCH/EHDI Program at (517) 335-9560.
  - B. <u>Medical Home's Responsibilities:</u>
    - 1. Ensure and coordinate the hearing rescreen with the family by one month of age or one month after discharge from the NICU.
    - 2. Aid screening hospital with recall efforts, if needed.

# V. ABNORMAL OUTPATIENT HEARING RESCREEN (in one or both ears)

- A. <u>Screening Hospital's Responsibilities:</u>
  - 1. Provide and explain written results to the infant's family.
  - 2. Ensure that the family received a copy of the *Michigan's Community Hearing Screening Program: Information for Parents* (MDCH-0474 7/01). Copies can be ordered, free of charge, from the MDCH/EHDI Program at (517) 335-9560.
  - 3. Provide the infant's family with a list of pediatric audiologists who can complete a comprehensive diagnostic audiologic evaluation as soon as possible, or no later than three months of age.
  - 4. Provide written notification to the infant's Medical Home.
  - 5. Report results to the MDCH/EHDI Program (FAX: (517) 335-8036).
- B. <u>Medical Home's Responsibilities:</u>
  - 1. Provide referral to a pediatric audiologist for a comprehensive diagnostic audiologic evaluation to be completed as soon as possible, or no later than three months of age.
  - 2. Refer the family to Children's Special Health Care if financial assistance is needed for diagnostic testing.
  - 3. Report results to the MDCH/EHDI Program (FAX: (517) 335-8036).

# VI. CONFIRMED HEARING LOSS

The Joint Committee on Infant Hearing defines the targeted hearing loss for universal newborn hearing screening programs as permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30 to 40 dB or more in the frequency region important for speech recognition (approximately 500 through 4000Hz).

- A. <u>Pediatric Audiologist's Responsibilities:</u>
  - 1. Provide and explain written results and recommendations of the diagnostic audiologic evaluation to the family at the time of diagnoses.
  - 2. Obtain a release of information for all facilities to which the infant will be referred for services or reports will be sent.
  - 3. Report results to the Medical Home and the MDCH/EHDI Program (FAX: (517) 335-8036).
  - 4. Counsel parent(s)/caregiver(s) on the effects of the hearing loss, communication, and the need for immediate intervention. If appropriate, earmold impressions may be taken at the diagnostic assessment to decrease delay in amplification intervention.
  - 5. Provide the family with a copy for the *Services for Children Who Are Deaf or Hard of Hearing: A Guide for Families and Providers (DCH-0376)*, which can be ordered, free of charge, from the MDCH/EHDI Program at (517) 335-9560.
  - 6. Provide a referral to educational services for children with hearing loss (Special Education Director of the Home School District or Intermediate School District).
  - 7. Provide a referral to *Early On* ® Michigan County Coordinator (1-800-EARLY-ON or 1-800-327-5966).

- 8. Counsel the parent(s)/caregiver(s) about family support through the Family Support Network (1-800-359-3722).
- 9. Counsel the parent(s)/caregiver(s) about financial assistance through Children's Special Health Care Services (1-800-359-3722).
- 10. Discussion of the importance of a genetic evaluation to determine etiology and other possible health related issues.
- 11. Schedule Audiologic Follow-up Appointments.
- 12. Refer parent(s)/caregiver(s) back to Medical Home for further consultation and referrals.
- B. <u>Medical Home's Responsibilities:</u>
  - 1. Provide a referral to an Otolaryngologist for medical management of hearing loss, determination of etiology, and medical clearance for hearing aid use (if intervention option is chosen by the family).
  - 2. Discuss the importance of genetic evaluation for determination of etiology and other possible health related issues.
  - 3. Provide other appropriate medical referrals that may include, but are not limited to, ophthalmology, cardiology, neurology, and nephrology.
  - 4. Monitor middle ear status to ensure the presence of middle ear effusion does not further compromise hearing.
  - 5. Monitor ongoing development of communication skills and other developmental milestones. Provide referrals related to parental/caregiver concerns or suspected delays.
  - 6. Ensure that a copy of *Services for Children Who Are Deaf or Hard of Hearing: A Guide for Families and Providers (DCH-0376)* has been provided to the family. Copies can be ordered, free of charge, from the MDCH/EHDI Program at (517) 335-9560.
  - 7. Coordinate and ensure, with the Service Coordinator (*Early On* ® Michigan), that referrals for early intervention services are made as soon as possible after diagnoses (see Guidelines for Early Intervention, 1-800-EARLY-ON or 1-800-327-5966).
  - 8. Ensure that the family maintains timely follow-up with an audiologist and other consultants. An immediate diagnostic audiologic evaluation should be scheduled when there is concern related to change in hearing.
    - a. Bilateral sensorineural hearing loss and permanent conductive hearing loss:
      - 1) Age 0-3: Every 3 months, after hearing loss is confirmed
      - 2) Age 4-6: Every 6 months, if intervention progress is satisfactory.
      - 3) Age 6 years or older: Every 6-12 months if progress is satisfactory.
    - b. Transient conductive hearing loss (e.g., otitis media with effusion), unilateral or bilateral:

Should be monitored after medical treatment (completion of antibiotic treatment, PE tubes, etc.), and/or at least on a 3-4 month basis until resolved and normal hearing is confirmed.

- c. Unilateral hearing loss (sensorineural or permanent conductive): Infants with unilateral hearing loss should be monitored every 3 months during the first year, then on a 6-months basis after the first year, to rule out changes in the normal hearing ear.
- 9. Monitor consistent use of amplification, sensory devices, and/or assistive technology if appropriate for the family.
- 10. Provide information on the infant's status to MDCH/EHDI (FAX: (517) 335-8036).
- 11. Monitor siblings for hearing loss.
- C. <u>Service Coordinator's Responsibilities (Early On ® Michigan)</u>
  - 1. Assist the family in development of an Individual Family Service Plan (IFSP) to address the communication needs of the child.
  - 2. Report name and contact information of the Service Coordinator to the Medical Home.
  - 3. Help facilitate family service coordination for the family.

#### References and Resources

American Academy of Pediatrics. (1999). Newborn and Infant Hearing Loss: Detection and Intervention (RE9846). *Pediatrics*, 103(2), 527-530. [On-line]. Available: <u>http://www.aap.org/policy/re9846.html</u>

American Academy of Pediatrics. (1992). Policy Statement: The Medical Home (RE9262). *Pediatrics*, 90(5), 774. [On-line]. Available: http://www.aap.org/policy/04992.html

Joint Committee on Infant Hearing (2000). Year 2000 position statement: Principles and guidelines for early hearing detection and intervention programs. *American Journal of Audiology*, 9, 9-29.

[On-line]. Available: http://www.infanthearing.org/jcih/

ATTACHMENT A: Flow Chart



Medical Home 7

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# ATTACHMENT B: JCIH Risk Indicators

JCIH risk indicators birth through age 28 days

- a. An illness or condition requiring admission of 48 hours or greater to a NICU.
- b. Stigmata or other findings associated with a syndrome known to include a sensorineural and or conductive hearing loss
- c. Family history of permanent childhood sensorineural hearing loss
- d. Craniofacial anomalies, including those with morphological abnormalities of the pinna and ear canal.
- e. In-utero infection such as cytomegalovirus, herpes, toxoplasmosis, or rubella.

JCHI risk indicators 29 days through 2 years

- a. Parental/Caregiver concern regarding hearing, speech, language, and or developmental delay.
- b. Family history of permanent childhood hearing loss.
- c. Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or Eustachian tube dysfunction.
- d. Postnatal infections associated with sensorineural hearing loss including bacterial meningitis.
- e. In-utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis.
- f. Neonatal indicators specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation (ECMO).
- g. Syndromes associated with progressive hearing loss such as neurofibromatosis, osteopetrosis, and Usher's syndrome.
- h. Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich's ataxia and Charcot-Marie-Tooth syndrome.
- i. Head trauma.
- j. Recurrent or persistent otitis media with effusion for at least 3 months.

# **GUIDELINES FOR HEARING SCREENING**

A goal of newborn hearing screening is to ensure that all newborns receive a hearing screen before discharge from the hospital or before one month of age. All hospitals performing hearing screening services should inform families that their newborn will have a hearing screen as part of the hospital's standard of care. The family should have the opportunity to waive this service if desired. The importance of newborn hearing screening and early identification of potential hearing loss should be relayed to parent(s)/caregiver(s) relative to its impact on speech, language, social, emotional, and cognitive development. Information on developmental milestones for speech and language development should also be made available to families of newborns. The brochure, *Michigan's Hearing Screening Program: Information for Parents* can assist with this information. Brochures are available, free of charge, in English, Spanish, and Arabic by contacting the Michigan Department of Community Health, Early Hearing Detection and Intervention (MDCH/EHDI) Program at (517) 335-9560.

Costs of hearing screening, rescreening and/or diagnostic services may be covered by third-party insurers, Medicaid, Early On, MI-Child, and/or Children's Special Health Care Services.

# I. PROTOCOL FOR INITIAL HEARING SCREEN

Hearing Screen: A pass/refer type of hearing test designed to identify newborns who require additional audiological assessment to rule out or confirm the presence of a hearing loss.

- A. <u>All Michigan hospitals that provide birthing services will complete a newborn</u> <u>hearing screen prior to discharge of the newborn</u>.
  - 1. Hospitals will provide the service 365 days/year.
    - a. AABR (Automated Auditory Brainstem Response).
    - b. DPOAE (Distortion Product Otoacoustic Emissions).
    - c. TEOAE (Transient Evoked Otoacoustic Emissions).
    - d. Combination of the above (a/b, a/c).
    - e. New objective hearing screening equipment approved by the MDCH/EHDI Program.
  - 2. Hospitals will follow the most current policies and procedures recommended by the American Academy of Pediatrics and Joint Committee on Infant Hearing (AAP 1999; JCIH, 2000). If a risk indicator for hearing loss is identified, it should be reported to the MDCH/EHDI, hospital's audiology consultant, and primary care physician (see Medical Home Attachment A: JCIH Risk Indicators).
  - 3. If the initial hearing screen indicates a refer result, a hearing rescreen should be completed in-hospital before discharge or as soon as possible, but no later than by one month of age or one month after discharge.
  - 4. Written results will be provided to the family, Medical Home and the MDCH/EHDI Program (FAX: (517) 335-8036).

# Hearing Screening 9

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- 5. Hospitals will provide the family with a copy of the *Michigan's Community Hearing Screening Program: Information for Parents* (MDCH-0474 7/01). Copies can be ordered, free of charge, from the MDCH/EHDI Program at (517) 335-9560.
- B. <u>Missed hearing screen:</u>
  - Missed hearing screen: A hearing screen not performed before discharge.
  - 1. Written notification of a missed hearing screen will be sent to the Medical Home by the screening hospital.
  - 2. Hospital personnel will retain initial responsibility for recall and completion of the hearing screen as soon as possible, but at least before one month of age.
  - 3. Written notification will be sent to the Medical Home and the MDCH/EHDI Program (FAX: (517) 335-8036) if the infant does not return for the hearing screen by one month of age or one month after discharge.
- C. <u>Newborns born outside of a birthing hospital:</u>
  - 1. Health professionals who provide birthing services outside of a hospital will ensure that a newborn hearing screen is completed within one month of birth.
  - 2. The provider who delivers the baby will provide the family with the name, address and telephone number of a local birthing hospital and/or audiology site where a hearing screen can be completed.
  - 3. The screening facility will report the outcome of the hearing screen to the Medical Home and the MDCH/EHDI Program (FAX: (517) 335-8036).
- D. <u>Newborns being transferred to another facility for care:</u>
  - 1. The birthing hospital will be responsible for reporting the hearing screening status and outcome to the receiving hospital.
  - 2. The receiving hospital to which the baby is transferred will be responsible for ensuring that the newborn has a hearing screen.
- E. <u>Newborns receiving care at tertiary care facilities:</u>
  - 1. The transferring hospital will be responsible for reporting the hearing screening status and outcome to the tertiary care facility.
  - 2. The tertiary care facility to which the baby is transferred will be responsible for ensuring that the newborn has a hearing screen.
  - 3. When an infant receives a hearing screen at the tertiary care facility and is reverse transferred to the hospital that provided his/her initial care, the tertiary care facility will be responsible for reporting the hearing screening outcome to the hospital to which the infant is reverse transferred.
  - 4. When the hearing screen cannot be provided at the tertiary care facility due to the medical status of the infant and the infant is reverse transferred to another hospital for further medical management, the tertiary care facility will be responsible for reporting the hearing screening status to the hospital to which the baby is reverse transferred.

# Hearing Screening 10

#### II. PROTOCOL FOR HEARING RESCREEN (in-patient and out-patient)

Hearing Rescreen: A refer result from the initial hearing screen that requires additional audiological assessment to rule out or confirm the presence of a hearing loss.

A. <u>Completion of Hearing Rescreen:</u>

All hearing rescreens should be completed in-hospital before discharge or as soon as possible, but no later than by one month of age or one month after discharge.

- B. <u>Scheduling Hearing Rescreen:</u> The hospital conducting the initial hearing screen will assume responsibility for scheduling hearing rescreens.
- C. <u>Need for Diagnostic Audiological Assessment:</u>

If the hearing rescreen indicates the need for diagnostic audiology assessment, the Program Manager in the hospital will provide the parent(s)/caregiver(s) with a written list of facilities that provide audiological assessment for infants and young children.

- 1. If possible, the hospital should assist the family, before discharge, in making an audiological appointment.
- 2. Written notification will be sent to the Medical Home and the MDCH/EHDI Program (FAX: (517) 335-8036) identifying the hearing rescreen results and need for diagnostic audiology assessment.
- 3. If hospital protocol requires that only the Medical Home relay hearing rescreen results to the parent(s)/caregiver(s), then it is the responsibility of the Medical Home to ensure that newborns, who do not pass the hearing rescreen, receive an audiological assessment.
- D. <u>Referral Resource for Hearing Rescreen:</u> The local health department and/or *Early On ®* Michigan (1-800-327-5966) may be offered as referral resources to help facilitate the hearing rescreen if there is difficulty establishing a Medical Home.
- E. <u>Unable to locate family for the hearing rescreen:</u>
  - 1. Two attempts will be made by the screening hospital to contact the family by phone and/or letter. A minimum of one notification will be made to the last known Medical Home.
  - 2. If no response is received from these attempts, a certified letter will be sent to the family.
  - 3. If there is no response from the certified letter or if it is undeliverable, the child will be considered lost to follow-up.
  - 4. The hospital screening program will notify the MDCH/EHDI Program and the last known Medical Home that the child was lost to follow-up.

# Hearing Screening 11

# III. REPORTING PROCESS

- A. <u>Documentation in Hospital:</u>
  - 1. Outcome of all newborn hearing screens, attempts, and refusals should be documented in the medical chart.
  - 2. The parent(s)/caregiver(s) should sign a waiver in the hospital if the hearing screen is refused as a service.
  - 3. The newborn hearing screen reporting card (i.e., part of newborn bloodspot card) should be completed relative the hearing screen result or incomplete hearing screen.
- B. <u>Notifications</u>:
  - 1. The hearing screen outcome will be reported, in writing to:
    - a. Medical Home within 10 days of the test date.
    - b. Parent(s)/Caregiver(s) before discharge or based on physician notification protocol but no later than 14 days of the test date.
    - c. The MDCH/EHDI Program within 14 days of the test date (FAX: (517) 335-8036).
  - 2. Bilateral Refers

If the newborn has a bilateral refer status, immediate notification will be sent to the MDCH/EHDI Program (FAX: (517) 335-8036) using the Bilateral Refer Form. This form contains a section for parental/caregiver release of information and referral authorization allowing for collaborative agencies to ensure follow-up diagnosis and intervention. The bilateral referral form should be completed with the current Medical Home information and alternate contact numbers for the parent(s)/caregiver(s)

# IV. PROGRAM MANAGEMENT

A. <u>Program Manager's Responsibilities:</u>

The Program Manager will hold ultimate responsibility for program coordination. If the Program Manager is other than a certified audiologist, collaboration with the hospital audiologist, if applicable, or a community audiologist for technical assistance should be established to help with program coordination.

- 1. Equipment maintenance and annual calibration.
- 2. Screener training.
- 3. Program/screener quality assurance.
- 4. Communication of hearing screen results with appropriate persons/agencies.
- 5. Statistical maintenance and analysis.

# Hearing Screening 12

# V. SCREENER PROFICIENCY AND EVALUATION

- A. <u>Responsibility for Training Screeners</u> The Program Manager, in consultation with an audiologist, will be responsible for the training of all screeners.
- B. <u>Evaluating Screener Competency</u> The Program Manager, in consultation with an audiologist, will be responsible for evaluating screener competency annually.

# C. <u>Content of Screener Training</u>

Training will include an in-depth presentation with clinical instruction.

- 1. The screener will complete a hearing screen on a <u>minimum</u> of five newborns with supervision.
- 2. Screeners will not become independent until they are proficient and competent in the hearing screening process. Screeners should achieve a 95% or better pass rate on a minimum of 10 newborns.
- 3. The screener will demonstrate the ability to inform parent(s)/caregiver(s) of test purpose and procedure.
- 4. The screener will demonstrate the ability to perform an equipment function check prior to usage.
- 5. The screener will be educated about the risk factors for hearing loss.
- 6. The screener will demonstrate accuracy in the record keeping process.
- 7. The screener will demonstrate accuracy in the operation of the hearing screening equipment.
- 8. The screener will demonstrate the ability to interpret hearing screen results and to notify parent(s)/caregiver(s) of outcome according to hospital protocol.
- 9. The screener will demonstrate the correct handling of the baby and hearing screening equipment (probe, earphone) placement.
- 10. The screener will demonstrate infection control procedures.

# VI. HEARING SCREENING CRITERIA

# A. <u>Screening Equipment</u>

Many of the manufacturers of automated hearing screening equipment have internal computerized settings for what constitutes a pass or refer for the hearing screen. The equipment manufacturer presents this criterion and the screener makes no decision. However, if a facility is not using automated hearing screening equipment, there will need to be judgment as to what response level constitutes a pass versus a refer outcome. Each program must have as a part of their program plan, documentation that identifies their testing/pass-refer criteria based on current technology and research findings. Related articles can be found in the reference page.

# B. <u>Risk Indicators</u>

When possible hearing screen results should also include known risk indicators for delayed onset or progressive hearing loss.

# C. <u>Calibration</u>

Each program must have documentation indicating the scheduled periodic calibration of hearing screening equipment.

D. <u>Definition of Hearing Loss</u>

The Joint Committee on Infant Hearing defines the targeted hearing loss for universal newborn hearing screening programs as permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30 to 40 dB or more in the frequency region important for speech recognition (approximately 500 through 4000Hz).

- VII. QUALITY INDICATOR
  - A. <u>Number of Newborns Screened</u> A minimum of 95% of newborns will have a hearing screen during the birth admission or prior to one month of age.
  - B. <u>Referral Rate</u> The referral rate for audiologic and medical evaluation should be <4% subsequent to a two-step hearing screen.
  - C. <u>Follow-Up</u>

Documentation will be present of the efforts to obtain follow-up on a minimum or 95% of the newborns who do not pass the hearing screen.

D. <u>Parental/Caregiver Information</u>

Parent(s)/Caregiver(s) will receive written results about the newborn hearing screen in the language of any group that comprises at least 10% of the obstetrical service population. Accommodations will be provided as outlined in the Americans with Disabilities Act (ADA, 2000).

#### References and Resources

American Academy of Pediatrics. (1999). Newborn and Infant Hearing Loss: Detection and Intervention, American Academy of Pediatrics Task Force on Newborn and Infant Hearing. *Pediatrics*, 103 (2), 527-530.

Americans with Disabilities Act. (2000). [On-line]. Available: http://www.usdoj.gov/crt/ada/publicat.htm

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#### **Related Articles**

American Speech-Language-Hearing Association. (1997). Guidelines for audiologic screening. Rockville, MD: ASHA.

Baker, S., Lesperance, M., & Kileny, P. (2000). Outcome of newborn hearing screening by ABR compared with four different DPOAE pass criteria. *American Journal of Audiology*, 9, 1-7.

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Gorga, M., Norton, S., Sininger, Y., Cone-Wesson, B., Folsom, R., Vohr, B., Widen, J., & Neely, S. (2000). Identification of neonatal hearing impairment: Distortion product otoacoustic emissions during the perinatal period. *Ear and Hearing*, 21(6), 400-424.

#### ATTACHMENT A: Flow Chart



Hearing Screening 16

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# GUIDELINES FOR DIAGNOSTIC AUDIOLOGIC EVALUATION

Audiologic evaluation of infants should be completed as soon as possible after a referral from the newborn hearing screening. The assessment should be completed by the time the child is three months of age to determine ear specific and frequency specific information regarding the type, degree and configuration of hearing loss. In the best interest of infants and children with hearing loss, these guidelines are strongly recommended.

Costs of hearing screening, rescreening and/or diagnostic services may be covered by third-party insurers, Medicaid, Early On, MI-Child, and/or Children's Special Health Care Services.

# I. ASSESSMENT SITE REQUIREMENTS

It is recommended that infants and young children be referred to diagnostic audiologic evaluation sites having the capacity to perform the full diagnostic assessment battery as listed below. It is also recommended that audiologists, who conduct diagnostic audiologic evaluations for the pediatric population, have adequate experience in evaluating newborns and very young infants. This will help circumvent delay in diagnoses and intervention, as well as compounding anxiety for parent(s)/caregiver(s).

# II. DIAGNOSTIC AUDIOLOGIC EVALUATION BATTERY

- A. Obtain a complete case history containing parental/caregiver report of emerging communication and auditory behaviors.
- B. Perform an otoscopic examination of the ears using great care not to scratch the ear canal.
- C. Perform Behavioral Observation Audiometry (BOA) to observe the infant's responsiveness to sound. At a minimum, attempt to obtain responses for frequency modulated pure tones of 500 Hz and 3000 Hz as well as for speech. Attempt to obtain a startle response to speech.
- D. Perform acoustic immittance measures, if possible, using a high frequency probe tone (tympanometry and acoustic reflex thresholds). If abnormal immittance measures are obtained, the infant should be referred to the Medical Home for diagnosis, treatment, and possible referral to an ENT for middle ear pathology prior to further testing. A one-month follow-up appointment should be scheduled to determine middle ear status and complete testing to rule out sensorineural hearing loss (Holt, Margolis, & Cavanaugh, 1991; Sprague, Wiley & Goldstein, 1985).
- E. Evoked Otoacoustic Emission (OAEs), Transient Evoked or Distortion Product.
- F. Diagnostic ABR (with conscious sedation if needed).
  - 1. High intensity click stimulus to assess latency and morphology of Waves I, III, V, and interwave intervals of Waves I-III, III-V and I-V.
  - 2. Threshold search with click stimulus.

# Diagnostic Audiologic Evaluation 17

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- 3. If the presence of middle ear pathology is suspected based on immittance test results, case history, or otoscopic exam, perform Wave V threshold search with bone-conducted click stimuli. If air-conducted and bone-conducted Wave V thresholds differ by 20 dB or more, the presence of conductive pathology should be suspected.
- 4. If possible, obtain tone burst thresholds at 500, 1000 and 4000 Hz bilaterally. (Stapells, 2000; Gorga, 1999; Stapells & Oats, 1997; Hood 1995; Gorga, Kaminski, Beauchaine, & Bergman, 1993; Ysunza & Cone-Wesson, 1987; Weber, 1982).
- III. RESULTS
  - A. <u>Normal/Within Normal Limits (infants with no risk indicators):</u>
    - 1. Discuss the test results with the parent(s)/caregiver(s). Include information on acquired, delayed onset, and progressive hearing loss and the need to monitor. Provide language and speech stimulation materials and milestone data.
    - 2. Prepare a complete and concise report of test results, recommendations and referrals. Parent(s)/Caregiver(s) should receive a copy of the diagnostic test results at the time of diagnoses with any written recommendations.
    - 3. Obtain a release of information for all facilities to which the infant will be referred for services or reports will be sent.
    - 4. Report results to the Medical Home and the Michigan Department of Community Health, Early Hearing Detection and Intervention Program (FAX: (517) 335-8036).
  - B. <u>Normal/Within Normal Limits ("at risk" infants and young children):</u>
    - 1. Retest "at risk" infants and young children at 3-month intervals for the first year and every 6 months until age 3 years. The JCIH outlines the following risk indicators for use with neonates or infants (29 days through 2 years):
      - a. Parental/Caregiver concern regarding hearing, speech, language, and or developmental delay.
      - b. Family history of permanent childhood hearing loss.
      - c. Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or eustachian tube dysfunction.
      - d. Postnatal infections associated with sensorineural hearing loss including bacterial meningitis.
      - e. In-utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis.
      - f. Neonatal indicators specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation (ECMO).

Diagnostic Audiologic Evaluation 18

- g. Syndromes associated with progressive hearing loss such as neurofibromatosis, osteopetrosis, and Usher's syndrome.
- h. Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich's ataxia and Charcot-Marie-Tooth syndrome.
- i. Head trauma.
- j. Recurrent or persistent otitis media with effusion for at least 3 months.
- 2. Prepare a complete and concise report of test results, recommendations and referrals. Parent(s)/Caregiver(s) should receive a copy of the diagnostic test results at the time of diagnoses with any written recommendations.
- 3. Obtain a release of information for all facilities to which the infant will be referred for services or reports will be sent.
- 4. Report results to the Medical Home and the MDCH/EHDI Program (FAX: (517) 335-8036).
- C. <u>Hearing Loss Identified</u>

The Joint Committee on Infant Hearing defines the targeted hearing loss for universal newborn hearing screening programs as permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30 to 40 dB or more in the frequency region important for speech recognition (approximately 500 through 4000Hz).

- 1. Prepare a complete and concise report of test results, recommendations and referrals. Parent(s)/Caregiver(s) should receive a copy of the diagnostic test results at the time of diagnoses with any written recommendations and contact information.
- 2. Obtain a release of information for all facilities to which the infant will be referred for services or reports will be sent.
- 3. Report results to the Medical Home and the MDCH/EDHI Program (FAX: (517) 335-8036).
- 4. Counsel parent(s)/caregiver(s) on the effects of the hearing loss, communication, and the need for immediate intervention. If appropriate, earmold impressions may be taken at the diagnostic audiologic evaluation to decrease delay in amplification intervention.
- 5. Provide parent(s)/caregiver(s) with a copy of the Services For Children Who Are Deaf or Hard of Hearing; A Guide to Resources for Families and Providers (DCH-0376), which can be obtained, free of charge, by calling MDCH/EHDI Program at (517) 335-9560.
- 6. Refer parent(s)/caregiver(s) to educational services for children with hearing loss (Special Education Director of the Home School District or Intermediate School District). Contact information is found in the *Services For Children Who Are Deaf or Hard of Hearing; A Guide to Resources for Families and Providers* (DCH-0376). Parent(s)/caregiver(s) should be strongly urged to visit different educational programs for the hearing impaired within their intermediate school district.

Diagnostic Audiologic Evaluation 19

- 7. Refer parent(s)/caregiver to *Early On* ® Michigan County Coordinator (1-800-EARLY-ON or 1-800-327-5966) for family coordination of services.
- 8. Counsel parent(s)/caregiver(s) about family support through the Family Support Network (1-800-359-3722).
- 9. Counsel parent(s)/caregiver(s) about financial assistance through Children's Special Health Care Services (1-800-359-3722).
- 10. Discuss the importance of a genetic evaluation to determine etiology and other possible health related issues.
- 11. Schedule audiologic follow-up monitoring appointment.
- 12. Refer parent(s)/caregiver(s) to the Medical Home for:
  - a. Medical intervention for transient conductive component (i.e., middle ear effusion) and/or referral to otolaryngologist for medical treatment with a follow-up audiologic evaluation after one month to determine status of middle ear and to rule out sensorineural hearing loss.

AND/OR (a. and/or b.)

- b. Referral to an Otolaryngologist for medical clearance for hearing aid use if parent(s)/caregiver(s) wish to pursue this intervention option. For audiologic results indicating auditory neuropathy (ABR fail OAE pass), the appropriateness of hearing aid use may be hard to determine (Hood, 2000).
- c. Discussion of the importance of a genetic evaluation to determine etiology and other possible health related issues.
- d. Referral for follow-up audiologic evaluation to monitor hearing status based on suggested audiological follow-up schedule.
- e. Review of *Guidelines for Newborn Hearing Services*, section on Guidelines for Medical Home and Guidelines for Early Intervention, for further information to ensure appropriate hearing health care for the infants and young children identified with hearing loss (Guidelines available through the MDCH/EHDI Program at (517) 335-9560).

# IV. HEARING AID OPTION

It is important for infants and children with hearing loss to have timely fitting of appropriate amplification when this intervention option is chosen. It is suggested that audiologists follow the recommendations of the Pediatric Working Group when providing amplification for infants and children with hearing loss. A systematic, quantifiable, and evidence-based approach with current technologies should be used when fitting children. The provision for audible, reliable, comfortable, and undistorted amplification for children can be determined through a four-stage process involving assessment, selection, verification, and validation (Bess, Chase, Gravel, Seewald, Stelmachowicz, Tharpe, & Hedley-Williams, 1994).

# Diagnostic Audiologic Evaluation 20

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- A. <u>Assessment:</u>
  - 1. Ear specific and frequency specific information regarding the type, degree, and configuration of a hearing loss should be obtained.
  - 2. Once the child receives medical clearance for hearing aid use, it is important to review the physician's notes to obtain information regarding the possibility of progressive hearing loss, evidence of multiple impairments, and structural deformities.
  - 3. Predictive methods for obtaining loudness level of discomfort (LLD) measurements with corrections for children should be determined.
  - 4. Real-ear measurements should be obtained, as soon as possible
  - 5. Unaided sound field levels, speech detection levels and speech perception levels should be obtained as soon as possible.
- B. <u>Selection Considerations:</u>
  - 1. Maximizing acoustic information for sound awareness and spoken language development is imperative, therefore binaural hearing aids should be recommended for binaural hearing loss, unless there is evidence that binaural amplification can not be tolerated.
  - 2. Small behind-the-ear hearing aid (s) with half moon ear hooks for ear specific and ear level amplification are preferred. Body style hearing aids may also be considered.
  - 3. Soft material earmolds are preferred and should be remade as the child grows.
  - 4. Hearing aids with the greatest flexibility in the electroacoustic parameters and signal processing should be considered. The specific method for selection used for fitting amplification for infants and young children should be based on rigorous research into the theoretical aspects of the specific method. References to selection considerations can be found in Pediatric Working Group Position Paper for Amplification for Infants and Children with Hearing Loss (Bess et al., 1994) and DSL method (Stelmachowicz, Dalzell, Peterson, Kopu, Lewis & Hoover, 1998).
  - 5. Safety features such as tamper resistant battery and volume control covers are recommended.
  - 6. Extended warranty and loss and damage coverage are recommended
  - 7. Parent/Caregiver kit with the contents including, but not limited to: stethoscope, dri-aid kit, battery tester, brush and pick are recommended.
  - 8. Retention system for keeping the hearing aid(s) secure to the head and to the body to prevent loss.
  - 9. Feedback management system.
  - 10. Directional/omni-directional microphone switching option.
  - 11. Remote FM microphone option and compatibility with other assistive device technology (e.g., direct audio input, telecoil/microphone-telecoil switching options).
  - 12. Insurance policies (Children's Special Health Care Services, Medicaid, Medicaid HMO and others third party insurers) should be contacted to

# Diagnostic Audiologic Evaluation 21

determine specific hearing aid reimbursement coverage for children identified with hearing loss.

C. <u>Verification:</u>

After the hearing aid has been selected and preset, the frequency-gain and output characteristics should be verified through probe-tube measurements (Stelmachowicz & Seewald, 1991; Moodie, Seewald & Sinclair, 1994). Aided sound field measurements for children over 6 months of age can also provide verification information but limitations should be considered (e.g., cooperation from the child, limited frequency resolution, poor test-retest, and limited gain and output level information from nonlinear hearing aids.

# D. Validation:

The purpose of validation is to demonstrate benefits/limitations of a child's aided listening abilities for perceiving the speech of others, the child's own speech, and sound awareness (Bess, et al, 1994). This information is usually obtained over time in various settings and from various people. A validation tool designed for the pediatric population is the Infant-Toddler: Meaningful Auditory Integration Scale (Zimmerman-Phillips, Osberger & Robbins, 1997).

E. Amplification Management and Maintenance

Families should be counseled regarding the need for audiologic follow-up to monitor the function, use, and appropriateness of amplification. Families should be counseled regarding the need to perform daily listening checks and the need for audiological reevaluation of a child's amplification. Periodic audiological reevaluation should include a recheck within 1-2 weeks after the initial fitting, and at 3 month intervals for children age 0-3 years; every 6 months for ages 4-6 years; and every 6-12 months for school age children. The frequency of follow-up may need to be increased if fluctuation/progression of the hearing loss is noted and/or if progress is questioned. Ongoing communication between the clinical audiologist and the members of the early intervention team is critical.

- F. Other Considerations:
  - 1. Assistive Technology

Families should be counseled regarding the benefits and limitations of assistive technology use in the home. Amplification options include but are not limited to, FM systems and alerting devices.

2. Amplification Orientation

Families should be counseled regarding hearing aid care, safety issues, troubleshooting techniques, incorporating use of hearing aids into the family routine, and other important topics related to hearing aid care (Elfenbein, 2000).

3. Amplification Follow-up

Families should be counseled regarding the need for amplification followup. A child's external ears change rapidly therefore earmolds will need to be remade to prevent acoustic leakage from occurring. When earmolds are remade, Real Ear to Coupler Difference measurements should be reevaluated to account for acoustic changes in the earmolds and for developmental changes in the child's external ear. During earmold Diagnostic Audiologic Evaluation 22 appointments, hearing aids should be evaluated through listening checks and electroacoustic checks in order to ensure proper function.

- V. SUGGESTED AUDIOLOGIC FOLLOW-UP AND MEDICAL MANAGEMENT Families should be counseled regarding the need for audiologic and medical follow-up. An immediate audiologic evaluation should be scheduled when there is concern related to change in hearing or hearing aid function.
  - A. <u>Bilateral sensorineural hearing loss and permanent conductive hearing loss:</u>
    - 1. Age 0-3: Every 3 months, after hearing loss is confirmed.
    - 2. Age 4-6: Every 6 months, if intervention progress is satisfactory.
    - 3. Age 6 years or older: Every 6-12 months if progress is satisfactory.
  - B. <u>Transient conductive hearing loss (e.g., otitis media with effusion), unilateral or bilateral:</u>

Should be monitored after medical treatment (completion of antibiotic treatment, PE tubes, etc.), and/or at least on a 3-4 month basis until resolved and normal hearing is confirmed.

C. <u>Unilateral hearing loss (sensorineural or permanent conductive):</u> Infants with unilateral hearing loss should be monitored every 3 months during the first year, then on a 6-months basis after the first year, to rule out changes in the normal hearing ear.

# VI. PERSONNEL REQUIREMENTS

At a minimum, an audiologist should complete the diagnostic audiologic evaluation. Any audiologist accepting infants and young children for initial diagnostic audiologic evaluation should have the ability to complete the procedures identified above. The following is preferred:

A. <u>Certification</u>

A qualified audiologist holds a Certificate of Clinical Competence from the American Speech-Language-Hearing Association (ASHA) or holds board certification by the American Board of Audiology or is a clinical fellow in audiology under the direct supervision of a certified audiologist.

- B. Experience in assessment of newborns and young infants
  - 1. Knowledge and experience in administering and interpreting ABRs and OAEs for the pediatric population.
  - 2. Affiliation with a medical facility in which sedation can be administered and monitored safely is needed.
- C. <u>Experience in recommending, fitting, and dispensing pediatric amplification</u>
  - 1. Experience in making earmold impressions for the pediatric population.
    - 2. Ability to provide hearing aids on a trial basis.
    - 3. Ability to provide loaner hearing aids.
    - 4. Access to repair of hearing aids for infants and young children in a timely manner.
- D. Knowledge of auditory development and auditory habilitation options

# Diagnostic Audiologic Evaluation 23

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American Speech-Language-Hearing Association. (1997). Guidelines for audiologic screening. Rockville, MD: ASHA.

Bess, F., Chase, P., Gravel, J., Seewald, R., Stelmachowicz, P., Tharpe, A., & Hedley-Williams, A. (1994). Pediatric Working Group. Amplification for infants and children with hearing loss, In R. Seewald (Ed.), A sound foundation through early amplification (pp. 13-31). Chicago, IL: Phonak.

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Hood, L. (2000). Auditory neuropathy: What is it and what can we do about it? [On-line]. Available: http://www.medschool.lsuhsc.edu/otor/audn-qa.html

Joint Committee on Infant Hearing. (2000). Year 2000 position statement: Principles and guidelines for early hearing detection and intervention programs. *American Journal of Audiology*, *9*, 9-29.

Moodie, K., Seewald, R., & Sinclair, S. (1994). Procedure for predicting real-ear hearing aid performance in young children. *American Journal of Audiology*, 3(1), 23-31.

Stelmachowicz, P., & Seewald, R. (1991). Probe-tube microphone measurements in children. *Seminars in Hearing*, 12, 491-496.

Stelmachowicz, P., Dalzell, S., Peterson, D., Kopu, J., Lewis, D., & Hoover, B. (1998). A comparison of threshold-based fitting strategies for nonlinear hearing aids. *Ear and Hearing*, 19(2), 131-138.

Zimmerman-Phillips, S., Osberger, M., & Robbins, A. (1997). Infant-Toddler: Meaningful Auditory Integration Scale (IT-MAIS). Sylmar, CA: Advanced Bionics Corp.

# **Related Articles**

Auditory Brainstem Response

Hood, L. (1995). Estimating auditory function with auditory evoked potentials. *The Hearing Journal*, 48(10), 10-42.

Stapells, D., & Oats, P. (1997). Estimation of the pure-tone audiogram by the auditory brainstem response: A review. *Audiology and Neuro Otology*, 2, 257-280.

Weber, B. (1982). Comparison of auditory brain stem response latency norms for premature infants. *Ear and Hearing*, 3(5), 257-267.

Diagnostic Audiologic Evaluation 24

#### Frequency-specific ABR

Gorga, M. (1999). Predicting auditory sensitivity from auditory brainstem response measurements. *Seminars in Hearing*, 20(1), 29-43.

Stapells, D. (2000). Frequency-specific evoked potential audiometry in infants In R. Seewald (Ed.), A sound foundation through early amplification (pp. 13-31). Chicago, IL: Phonak.

#### Bone Conduction ABR

Gorga, M., Kaminski, J., Beauchaine, K., & Bergman, B. (1993). A comparison of auditory brain stem response thresholds and latencies elicited by air- and bone-conduction stimuli. *Ear and Hearing*, 14, 85-94.

Ysunza, A., & Cone-Wesson, B. (1987). Bone conduction masking for brainstem auditory-evoked potentials (BEAP) in pediatric audiological evaluations. Validation of the test. *International Journal of Pediatric Otorhinolarynology*, 12, 291-302.

#### **Immittance Measurements**

Holte, L., Margolis, R., & Cavanaugh, R. (1991). Developmental changes in multifrequency tympanograms. *Audiology*, 30, 1-24.

Sprague, B., Wiley, T., & Goldstein, R. (1985). Tympanometric and acoustic-reflex studies in neonates. *Journal of Speech and Hearing Research*, 28, 265-272.

Diagnostic Audiologic Evaluation 25

# GUIDELINES FOR GENETIC EVALUATON REFERRAL

The prevalence of permanent hearing loss in infants is estimated to be 2-3/1000 in the United States (Finitzo et al., 1998; Prieve et al., 2000). One or both ears may be affected. Until the 1970's when universal immunization was introduced, maternal rubella infection caused a significant proportion of congenital hearing loss. Today, about 50% of congenital and early onset hearing loss is attributable to genetic factors (Marazita et al, 1993), and considerable progress has been made in identifying genes for deafness over the last few years.

Genetic hearing loss is usually divided into two categories. In approximately 70% of cases present at birth, the hearing loss occurs as an isolated trait and is called *nonsyndromic*. The auditory deficit in nonsyndromic hearing loss can vary, but is most often sensorineural. It can be unilateral or bilateral, congenital or late-onset, and stable or progressive. The remaining 30% of hearing loss is classified as *syndromic*, meaning that it occurs as part of a collection of anomalies (i.e., physical features and/or medical conditions). Syndromic hearing loss varies widely and can be conductive, sensorineural or mixed; unilateral or bilateral; congenital or late-onset; and stable or progressive (Resendes et al, 2001). There are at least 75 genetic types of nonsyndromic hearing loss (Gorlin, et al, 1995; Stell & Kros, 2001). Children born with hearing loss often have the same physical and cognitive development as those who are born hearing.

#### I. PURPOSE OF REFERRAL

The primary purpose of a genetic evaluation is to investigate the etiology of the hearing loss in order to anticipate whether the child has, or is at risk for, other medical conditions. Examination by a skilled dysmorphologist may uncover subtle indicators of a genetic syndrome. While genetic evaluation does not always pinpoint an exact etiology, it can yield important information about the hereditary nature of a hearing loss. Establishing a genetic diagnosis whenever possible is more important now than in the past. New information about the pathophysiology and natural history of the different forms of hereditary hearing loss is rapidly emerging. Therapeutic interventions to reduce the risk of complications associated with specific etiologies may someday be available.

Other important benefits of the genetic evaluation are to 1) identify other family members, particularly young siblings, who should be evaluated for possible hearing loss or associated medical conditions, and 2) provide recurrence information for family planning. A referral to a genetics center allows genetic tests to be offered in conjunction with appropriate counseling.

#### II. WHEN TO MAKE A REFERRAL

A. <u>Position Statements</u>

The Joint Committee on Infant Hearing has recommended that families be offered the option of genetic evaluation and counseling by a medical geneticist where

Genetic Evaluation Referral 26

thorough physical and laboratory investigations fail to define the etiology of hearing loss. (2000, p. 16). In a report produced for the Maternal and Child Health Bureau (MCHB) of the Federal Health Resources and Services Administration (HRSA), the American College of Medical Genetics recommends that all children with confirmed hearing loss be referred for genetic evaluation and counseling to a genetics team that typically includes a geneticist and genetic counselor. Accordingly, it is reasonable to refer all infants with confirmed permanent hearing loss (i.e., permanent sensorineural, conductive or mixed hearing loss) for genetic evaluation after discussion with the parent(s)/caregiver(s) about the potential benefits and limitations of the genetic evaluation and counseling process.

B. <u>Prioritizing the Appointment</u>

The Medical Home should facilitate referral for genetic evaluation as soon as possible once the diagnosis of permanent hearing loss has been confirmed, ideally by 3 months of age. It is important to prioritize the timing of the appointment in light of many other appointments the family members may have, and their adjustment to the diagnosis.

1. <u>Reasons for Immediate Referral</u>

Reasons for immediate genetic referral include, but are not limited to the following:

- a. Suspected genetic diagnosis associated with additional health conditions.
- b. Parent(s)/Caregiver(s) are asking for information about the possible cause and/or want to know the chances of recurrence for family planning and appropriate medical care for other family members, especially children.
- c. Parental consanguinity (i.e., the parents share a common biological ancestor).
- d. Relative with a syndromic cause of hearing loss or other manifestations of a syndrome known to include hearing loss.
- e. Hearing loss in a child exposed to aminogylcosidic antibiotics (i.e., antibiotics from the -mycin group used to fight certain infections). Susceptibility to hearing loss induced by these antibiotics can be inherited.
- f. Need for assistance with interpretation of genetic or other test results ordered by the Medical Home or pediatric specialists
- 2. <u>Possible issues with families with a negative family history of hearing loss</u> The majority of genetic hearing loss is transmitted as an autosomal recessive trait. Autosomal refers to genes located on non-sex chromosomes; recessive means that both copies of a gene, in a given pair, must be affected for the person to have the condition. Therefore, there is often no history of similar hearing loss in a child's biological parents or other close relatives. It is estimated that 90% of children with hearing loss have parents who are hearing (Gorlin, Toriello & Cohen, 1995). In the absence of a family history, the news that their child has hearing loss can come as a shock to parent(s)/caregiver(s) and they often experience stages Genetic Evaluation Referral 27

of grieving with regard to the loss of their anticipated "healthy" baby. When a diagnosis of hearing loss is made, parent(s)/caregiver(s) are often overwhelmed by the number of medical appointments needed for their child and the amount of information and advice they are receiving from a variety of professionals, friends, and family. This, in addition to an absence of family history, and the social stigma sometimes associated with genetic conditions, may make parent(s)/caregiver(s) reluctant to pursue a genetic consultation. It is important for the Medical Home to be sensitive to the family's adjustment process as they coordinate the overall medical management of the child, while communicating the importance of a genetic evaluation for assessing other potential health risks and possibly, optimal interventions.

3. Possible issues with families with a positive family history of hearing loss Parent(s)/Caregiver(s) who are deaf may view hearing loss as a difference that is a normal variation in humans, not a disorder. Since it is a common misconception that the only purpose of a genetic evaluation is to reduce the recurrence of a condition in a family, parent(s)/caregiver(s) may be hesitant to accept a genetic referral. The Medical Home should counsel the family about the role of the genetic evaluation in determining potential medical management and intervention strategies.

# III. RESPONSIBILITIES FOR THE REFERRAL PROCESS

- A. <u>The Medical Home's Responsibilities</u>
  - 1. Obtain a family history and past medical history to assess the urgency of genetic referral.
  - 2. Discuss the importance of a genetic referral for investigating the etiology as a basis for decisions that might affect medical and audiologic intervention.
  - 3. Refer parent(s)/caregiver(s) to a genetics center (listed on page 8).
  - 4. Ensure that the Service Coordinator is aware of all medical implications.
- B. <u>Audiologist's Responsibilities</u>
  - 1. Complete an audiologic report describing the hearing loss (e.g., type, degree, and configuration) and audiologic tests performed (e.g., tympanometry, auditory brainstem response, otoacoustic emissions).
  - 2. Provide the Medical Home with a copy of the audiologic report and recommend to the Medical Home the need for genetic referral as it relates to the overall implications for the medical and intervention management of the child.
  - 3. Counsel the family regarding the role of a genetics evaluation in determining the etiology of the hearing loss and identifying other health-related issues.

# Genetic Evaluation Referral 28

# C. <u>Service Coordinator's Responsibilities (Early On ® Michigan)</u>

- 1. Counsel the family regarding the role of a genetics evaluation in determining the etiology of the hearing loss and identifying other health-related issues.
- 2. Ensure that the plan for intervention services takes into account any information available from genetic counseling, if known.

# IV. WHERE TO MAKE THE GENETIC REFERRAL

Six regional pediatric genetic centers are located in southeast and mid-Michigan and also conduct outreach clinics in other geographic areas as noted on page 8 (Genetic Clinic Contact Information). The Hereditary Disorders Program at the Michigan Department of Community Health helps to coordinate a statewide network of clinics that can provide genetic evaluation and counseling. For more information contact the state genetics coordinator at (517) 335-8887 or visit http://www.mdch.state.mi.us/dch/clcf/hdp/.

# V. GENETIC EVALUATION

- A. <u>Professionals Involved</u>
  - A comprehensive genetic evaluation with genetic counseling requires a multidisciplinary approach. Specific genetic professionals include:
    - 1. Clinical Geneticist: Physicians who are certified by the American College of Medical Genetics after completing a two year fellowship in clinical genetics, which trains them to diagnose and treat genetic conditions. Clinical geneticists are usually also trained and board certified in one of the following disciplines: pediatrics, internal medicine, oncology, pathology, or obstetrics/gynecology.
  - 2. Genetic Counselor: Professionals who have graduated from an accredited Master's level genetic counseling graduate program and are certified (or eligible for certification) through the American Board of Genetic Counseling. Genetic counselors are trained to recognize and assess genetic conditions in an individual and family, educate patients about genetic conditions and genetic testing, and help patients and families cope with the diagnosis of a genetic condition.
- B. <u>Evaluation Process</u>

Typically, the genetic evaluation includes:

- 1. Reviewing pertinent medical records.
- 2. Taking a complete, 3-4 generation family history, with emphasis on key genetic and phenotypic features (e.g. visual anomalies, specific facial dysmorphology, endocrine abnormalities, cardiac symptoms, etc.) as well as audiometric characteristics of hearing loss in relatives.
- 3. Taking a comprehensive patient medical and developmental history, including assessment of possible infectious etiologies.
- 4. Performing a physical and dysmorphology examination.

# Genetic Evaluation Referral 29

- 5. Discussing the benefits, risks, limitations, and cost of genetic testing with parent(s)/caregiver(s).
- 6. Ordering genetic and/or other laboratory tests as indicated.
- C. <u>Genetic Counseling and Follow-up</u>

After a genetic diagnosis is established, genetic counseling is provided to address the family's questions and concerns, including an explanation of the natural history of the condition, pattern of inheritance, medical implications, and possibility of recurrence or associated health risks in other relatives. Sometimes a precise genetic diagnosis cannot be made, even after thorough evaluation and testing. Often genetic counseling can still provide helpful information about differential diagnoses, recurrence, medical management, and importantly, available community, state, and national resources for information, support, and services. In addition, the genetics staff arranges for referrals (through the Medical Home) to other specialists when indicated, to help further evaluate etiology, and/or follow-up evaluations through the genetics clinic.

D. Funding

The cost of the genetics consultation and testing is often covered by third-party insurers, Children's Special Health Care Services and Medicaid. The genetic counselor may be able to help identify and coordinate sources of payment for families without health insurance.

E. <u>Reporting</u>

A summary of the genetic evaluation, including test results, is communicated to the Medical Home via letter or clinic consultation note. Parent(s)/Caregiver(s) may also receive a copy and should request one if it is not provided. In addition, at the parents'/caregivers' request, this information can be sent to other specialists involved in their child's care. The genetics professionals also communicate verbally with the Medical Home and/or other specialists as needed.

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# Genetic Evaluation Referral 31

#### ATTACMENT A: Website Resources

American College of Medical Genetics. Position statement on Universal Newborn Hearing Screening. http://www.faseb.org/genetics/acmg/pol-35.htm

Gene Letter. This is an online magazine that focuses on the scientific, medical and bioethical issues related to genetics. <u>http://www.geneletter.com/index.epl</u>

Hereditary Hearing Loss Homepage: Papers, meeting dates and other information related to research on both syndromic and nonsyndromic hearing loss. <u>http://www.uia.ac.be/dnalab/hhh/</u>

Information for Genetic Professionals. This site, posted by the University of Kansas Medical Center, contains clinical, research, and educational resources for genetic counselors, clinical geneticists, and medical geneticists. <u>http://www.kumc.edu/gec/geneinfo.html</u> <u>http://www.kumc.edu/gec/glossary.html</u>

NCHPEG. The National Coalition for Health Professional Education in Genetics is a national effort to promote health professional education and access to information about advances in human genetics. <u>http://www.nchpeg.org/</u>

National Society of Genetic Counselors, Inc. This site provides general information about genetic counseling, as well as information about genetic counseling resources. http://www.nsgc.org/

OMIM (Online Mendelian Inheritance in Man). This database, authored and edited by Dr. Victor A. McKusick and his colleagues at Johns Hopkins and elsewhere, is a catalog of human genes and genetic disorders. It was developed for the World Wide Web by the National Center for Biotechnology Information. <u>http://www3.ncbi.nlm.nih.gov/omim</u>

Genetic Evaluation Referral 32
#### <u>ATTACHMENT B:</u> Genetic Clinic Contact Information

Detroit Medical Center (Detroit) Children's Hospital: Division of Genetics & Metabolism (313) 745-4513

Henry Ford Hospital (Detroit with outreach clinics in Port Huron, Saginaw, Bay City, & Midland) Department of Medical Genetics (313) 916-3188

Michigan State University (East Lansing with outreach clinics in Flint & Kalamazoo) Genetic Counseling Clinic (517) 353-2030

Spectrum Health (Grand Rapids with outreach clinics in Big Rapids & Muskegon) Genetic Services (616) 391-2700

University of Michigan (Ann Arbor with outreach clinics in Marquette, Traverse City & Gaylord) Pediatrics Genetics Clinic (734) 764-0579

William Beaumont Hospital (Royal Oak) Pediatric Genetics Clinic (248) 551-0487

Genetic Evaluation Referral 33

# **GUIDELINES FOR EARLY INTERVENTION**

The goals of newborn hearing screening are to provide a hearing screen to all newborns before one month of age, to ensure that all newborns who do not pass the birth admission hearing screen obtain a diagnostic outcome before three months of age, and for all infants identified with hearing loss to obtain intervention services before six months of age (See Attachment C for eligibility). The Joint Committee on Infant Hearing defines the targeted hearing loss for universal newborn hearing screening programs as permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30-40 dB or more in the frequency region important for speech recognition (approximately 500-4000 Hz). Identifying a baby with hearing loss as early as possible, can allow early intervention strategies to optimize the critical language learning years of a young child. The goal of early intervention is to provide every child with a hearing loss the opportunity to develop an effective communication system. Thus, a primary focus of early intervention is on providing parent(s)/caregiver(s) with the information and skills needed to communicate naturally with their child, as they are engaged in everyday activities.

Research on brain development indicates that the critical time for learning language is from birth to three years of age. Without early identification of hearing loss and subsequent intervention, children are at risk of missing the opportunity for communication and socialization development during early life experiences. The wealth of learning that takes place as the young child develops language is the basis for later literacy and educational development. Likewise, the communication skills, academic achievement, social skills and level of self-esteem acquired by the child will be important factors in determining life options and success as an adult.

## I. EARLY INTERVENTION PROCESS

# A. Early On ® Michigan

Upon confirmation of hearing loss, a referral to *Early On* ® Michigan, at 1-800-EARLY ON (1-800-327-5966), must take place within 2 working days. An interim Service Coordinator will facilitate the assessment and individualized program planning for the family (See Attachment A: *Early On* ® Michigan Referral Process to Intervention). When the parent(s)/caregiver(s) sign the initial consent for educational evaluation, they will receive a booklet describing their legal rights (Procedural Safeguards). The state and federal governments have established timelines from referral to assessment to service provision. It is strongly recommended that Service Coordinators, working with families, have knowledge of local early intervention programs/services for young children with hearing loss, as well as available resources and service agencies. This information can be found in the *Services For Children Who Are Deaf or Hard of Hearing; A Guide to Resources for Families and Providers* (DCH-0376), which can be obtained, free of charge, by calling the MDCH/EHDI Program at (517) 335-9560.

B. <u>Individualized Family Service Plan (IFSP)</u> The Service Coordinator will assist the family in developing an Individualized Family Service Plan (IFSP). This document will list the services to be provided

to the child and the family, based on the child's and family's abilities and needs. The IFSP needs to address the communication needs of the child and his/her family so effective communication can begin immediately. To ensure full participation in the IFSP, parent(s)/caregiver(s) should be informed of communication choices and the importance of their role in making that choice. This information sharing should continue as the interventionists and parent(s)/caregiver(s) work as a team, while monitoring the child's communication development.

#### II. PRINCIPLES OF EFFECTIVE EARLY INTERVENTION

Infants with confirmed hearing loss should receive intervention as soon as possible or within 45 days of identification of the hearing loss. Professionals in both health care and education, who possess expertise in hearing loss and its effects on early development, should provide this service. Early intervention programs should be family-centered and interdisciplinary. Family-centered care involves the following:

- 1. Recognizing that the family is the constant in a child's life while the service systems and personnel within those systems fluctuate.
- 2. Facilitating parent/caregiver-professional collaboration at all levels of health care and in educational intervention.
- 3. Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.
- 4. Recognizing family strengths and individuality and respecting different methods of coping.
- 5. Sharing with parent(s)/caregiver(s), on a continuing basis and in a supportive manner, complete and unbiased information on the various modes of communication used with children who are hearing impaired and the common beliefs about each.
- 6. Encouraging and facilitating family-to-family support and networking.
- 7. Understanding and incorporating the development needs of infants, children and their families into early intervention services.
- 8. Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.
- 9. Assurance that the design of early intervention services is flexible, accessible, and responsive to family needs.

Professionals should provide parent(s)/caregiver(s) with spoken, written, and/or signed information, as needed, to enable them to make informed choices related to communication options, educational programs, and other services (e.g. Family Support Network). At the diagnostic audiologic evaluation, the audiologist should provide the family with a copy of the *Services For Children Who Are Deaf or Hard of Hearing; A Guide to Resources for Families and Providers* (DCH-0376), which can be obtained, free of charge, by calling the MDCH/EHDI Program at (517) 335-9560. The Medical Home and the Service Coordinator should ensure that the family has received a copy of the resource guide. The resource guide is a starting point for parent(s)/caregiver(s) to obtain information about services. The Service Coordinator should ensure that the family has Early Intervention 35

access to other information on general child development as well as the unique needs related to hearing loss and language development. This can be facilitated by the family 1) working with professionals, 2) interacting with other parent(s)/caregiver(s) of children with hearing impairment, 3) interacting with adults who are deaf or hard of hearing, and 4) working with organizations or agencies serving as resources on hearing impairment and deafness. In supplying information to families, professionals must recognize and respect the family's natural transitions through the grieving process at the time of initial identification of hearing loss and at different intervention decision-making stages (Cherow, Dickman, & Epstein, 1999; Luterman, 1985; Luterman & Kurtzer-White, 1999).

A. <u>Audiologic Intervention</u>

For parent(s)/caregiver(s) who decide to provide their child with amplification, early intervention services can provide a vital opportunity for stimulation of the child's auditory system. This can be accomplished through the use of hearing aids, FM systems, cochlear implants or other assistive technology. Information regarding these options will be made available to parent(s)/caregiver(s) by the diagnostic audiologist who will provide them with a copy of the *Services For Children Who Are Deaf or Hard of Hearing; A Guide to Resources for Families and Providers* (DCH-0376), which can be obtained, free of charge, by calling the MDCH/EHDI Program at (517) 335-9560. Input from the interventionists and the parent(s)/caregiver(s) will assist the audiologist in assessing the child's hearing status, the child's benefit from the current amplification system and the need for adjustments. The following best practices are recommended:

- 1. Amplification
  - a. Binaural hearing aids are recommended for children with bilateral hearing loss. Use of amplification should be initiated within one month of confirmation of hearing loss, or as soon as possible.
  - b. Audiologic management should include real-ear measures and electroacoustic analysis and/or reprogramming of the child's hearing aids.
  - c. Aided and unaided responses across the speech frequencies should be obtained, as early as possible, but no later than twelve months following confirmation of a hearing loss. Behavioral response for ear-specific information (both aided and unaided) should be obtained as early as possible, but no later than 2 years after confirmation of hearing loss. This may mean frequent initial visits to the audiologist.
  - d. New earmolds should be obtained as frequently as necessary, dependent on the growth of the child.
  - e. For audiologic results indicating auditory neuropathy (ABR fail, OAE pass), the appropriateness of hearing aid use may be hard to determine (Hood, 2000).
  - f. Amplification Management and Maintenance

Families should be counseled regarding the need for audiologic follow-up to monitor the function, use, and appropriateness of amplification. Families should be counseled regarding the need to perform daily listening checks and the need for audiological re-evaluation of a child's amplification. Periodic audiological re-evaluation should include a recheck within 1-2 weeks after the initial fitting, and at 3 month intervals for children age 0-3 years; every 6 months for age 4-6 years; and every 6-12 months for school age children. The frequency of follow-up may need to be increased if fluctuation/progression of the hearing loss is noted and/or if progress is questioned. Ongoing communication between the clinical audiologist and the members of the early intervention team is critical.

2. Audiologic Monitoring

All children with identified hearing loss (i.e., hearing levels > or = to 25 dB HL, unilateral or bilateral, permanent or fluctuating) should receive periodic audiologic monitoring as per the suggested schedule listed below. An immediate audiologic evaluation should be scheduled when there is concern related to change in hearing or hearing aid function.

- a. Bilateral sensorineural hearing loss and permanent conductive hearing loss:
  - 1) Age 0-3: Every 3 months, after hearing loss is confirmed.
  - 2) Age 4-6: Every 6 months, if intervention progress is satisfactory.
  - 3) Age 6 years or older: Every 6-12 months if progress is satisfactory.
- b. Transient conductive hearing loss (e.g., otitis media with effusion), unilateral or bilateral: Should be monitored after medical treatment (completion of

antibiotic treatment, PE tubes, etc.), and/or at least on a 3-4 month basis until resolved and normal hearing is confirmed.

- c. Unilateral hearing loss (sensorineural or permanent conductive): Infants with unilateral hearing loss should be monitored every 3 months during the first year, then on a 6-months basis after the first year, to rule out changes in the normal hearing ear.
- B. Educational Intervention
  - The mounting evidence for the crucial nature of early experiences in brain development provides the impetus to ensure learning opportunities for infants and young children with hearing loss. Intensive early intervention can positively alter the cognitive and developmental outcomes. Early intervention services should be designed to meet the individualized needs of families and infants, including addressing acquisition of communicative competence, social skills, emotional well-being, and positive self-esteem (Karchmer & Allen, 1999). Effective intervention should also provide ongoing assessment through frequent evaluation Early Intervention 37

of a child's progress by the parent(s)/caregiver(s) and interventionists to ensure that a child is progressing at an expected rate. The six frequently cited principles of effective early intervention follow (Meadow-Orleans, Mertens, Sass-Lehrer, & Scott-Olson, 1997; Moeller & Condon, 1994; Ramey & Ramey, 1992, 1998; Stredler-Brown, 1998; Tomblin, Spencer, Flock, Tyler, & Gantz, 1999).

- Developmental Timing This refers to the age at which services begin and the duration of enrollment. Programs that enroll infants at younger ages and continue longer are found to produce the greatest benefits.
- 2. Program Intensity

The amount of intervention is measured by multiple factors, such as the number of home visits/contacts per week for the infant and family's participation in intervention. Greater developmental progress occurs when the infant and family are actively and regularly involved in intervention.

3. Direct Learning

This principle encompasses the idea that center-based and home-based learning experiences are more effective when there is direct (provided by trained professionals) as well as indirect intervention.

- 4. Program Breadth and Flexibility This notes that successful intervention programs offer a broad spectrum of services and are flexible and multifaceted to meet the unique needs of the infant and family, including infants with additional disabilities beyond their hearing loss.
- 5. Infant and Family Individual Differences The rate of progress and benefits from the program will differ. Not everyone progresses at the same rate nor benefits from the programs to the same extent.
- 6. Environmental Support and Family Involvement The benefits of early intervention continue over time depending on the effectiveness of existing supports such as family involvement and environmental supports such as home, school, peers and Medical Home.
- C. <u>Communication Skills Intervention Components</u>

The unique features of an early intervention program for children who are deaf or hard of hearing should include the following components. The family, supported by the IFSP team will determine which specific components would be part of each child's intervention plan.

1. Language Skills Development

The development of communication skills, particularly language skills, is fundamental to a child's academic, social, cognitive, and linguistic development, as well as mental and physical well-being and will determine, to a great degree, whether that child can become a productive, fulfilled, and capable adult. A child's communication begins developing from birth through natural interactions and conversations between the child and his/her caregivers. Effective interaction between the caregiver Early Intervention 38 and the young deaf or hard of hearing child is extremely important if language is to develop. Children express communicative intent through a variety of gestures, facial expressions, and vocalizations. The growth in both oral and/or sign language development should be consistent with the developmental expectations for the child's age and cognitive abilities. Language development should include acquisition of phonologic (for spoken language), visual/spatial/motor (for signed language), morphologic, semantic, syntactic, and pragmatic skills. Communication can be facilitated through:

- a. Teaching parent(s)/caregiver(s) to respond to these expressed messages appropriately. This will help the child develop an effective communication system. Topics covered should include prelinguistic (selective attention and turn taking) development.
- b. Providing parent(s)/caregiver(s) with information specific to language development and with family-involved activities that facilitate language. As parent(s)/caregiver(s) learn about how communication develops, how to foster and stimulate effective caregiver-child interactions, and how to monitor and evaluate their child's communication they will reach a decision regarding communication methodology that is appropriate for their child and the entire family.
- 2. Auditory Skills Development

Young children who are deaf or hard of hearing need the opportunity to learn to use their amplified residual hearing or a cochlear implant to gain meaning from the world of sound. The auditory program should educate parent(s)/caregiver(s) and children on the development of the hierarchy of listening skills:

- a. Detection: The process of determining whether sound is present or absent.
- b. Discrimination: The process of perceiving the differences between sounds, especially speech sounds.
- c. Identification: The process of learning the labels or names for what has been heard.
- d. Comprehension: The process of understanding the meaning of acoustic messages.
- 3. Hearing Aid Program

Parent(s)/Caregiver(s) need to learn how the hearing aids work, how to care for them, and how to operate them. Parent(s)/Caregiver(s) also need information on related topics, such as understanding the degree and nature of their child's hearing loss, the importance of well functioning hearing aids for spoken language development, and how speech is perceived. They also need information on assistive technology, including but not limited to: FM listening devices, tactile aids, t-coils, captioning, alerting devices, and cochlear implants. In supplying information to families, it is Early Intervention 39 important for professionals to prioritize information presentation in light of the vast array of new information families receive after the initial identification of hearing loss in their child.

4. Parent(s)/Caregiver(s) Support

Parent(s)/Caregiver(s) are the best models for their children. A very important role of the early interventionist is to offer parent(s)/caregiver(s) guidance and resources to enable them to develop the skills needed to provide their child with an effective communication system. Interventionists are encouraged to be aware of the uniqueness of each family's dynamics and the impact that a child with a hearing loss has on the dynamics. As stated earlier, parent(s)/caregiver(s) should be given unbiased information on each communication option (American Sign Language, Auditory/Oral, Auditory/Verbal, Cued Speech, and Manually Coded English). After parent(s)/caregiver(s) decide on a communication approach, they should be encouraged to learn as much as they can about that approach and use it regularly in communication at home. The communication approach selected should be reevaluated if the child is not developing communication at the expected rate.

a. Ongoing information

Parent(s)/Caregiver(s) should be provided with ongoing information and experiences, as needed, in the following areas:

- 1) Communication choices, in an unbiased manner
- 2) Opportunities to meet older children or adults, with varying degrees of hearing loss, who communicate using spoken language
- 3) Opportunities to meet older children or adults who communicate through the use of sign language
- 4) How to access educational services
- 5) How to access public or private services for audiological management, hearing aids and other assistive devices, speech therapy, and/or sign language tutoring/classes
- 6) Agencies that may provide financial assistance
- 7) Special education laws and parents'/caregivers' rights
- 8) Community support systems and programs (e.g., counseling services, social services, and infant mental health services)

These resources can be found in the Handbook, *Services For Children Who Are Deaf or Hard of Hearing; A Guide to Resources for Families and Providers*, which can be obtained, free of charge, by calling the MDCH/EHDI Program at (517) 335-9560.

D. <u>Medical Intervention Coordination</u>

Ongoing medical intervention is an important part of the overall early intervention plan for young children with hearing loss. It is important for the family to have a Medical Home for the medical management of the child and monitoring of Early Intervention 40 ongoing developmental milestones. The Medical Home should be involved in collaborating efforts related to family service coordination. The Medical Home can provide referrals related to specialty care (e.g., ophthalmology, speech pathology, audiology, etc.), can monitor the child for the presence of middle ear effusion so that hearing is not further compromised, and can counsel the family regarding the benefits of genetic evaluation (i.e., which may provide information on etiology of hearing and other related medical conditions). The Medical Home also plays an important role in reinforcing the importance of early intervention services and monitoring ongoing developmental progress.

# E. <u>Standards For Early Intervention Service Providers</u>

1. Trained Personnel

It is critical to the success of early intervention programs to have trained personnel providing the intervention. Since newborn hearing screening can help to identify children with hearing impairment at a very young age, it provides an opportunity to prevent the severe language delay that occurs with later identification. In order to optimize the opportunity for communication development during these early months, the intervention services providers must have the knowledge and experience to: 1) respond to parents'/caregivers' questions, 2) provide them with information on hearing impairment and its effects, and 3) model the ways in which they can provide language stimulation during daily activities with their baby.

2. Knowledge and Skills of Service Providers Standards for early intervention service providers for young children who are deaf/hard of hearing and their families have been reported in the "Early Intervention Protocol" document published by the State of Colorado. This list provides a comprehensive guide for knowledge and skills of staff, but can also be used as an inclusive guide to the breadth of information which should be shared, over time, with the family of the newly identified child with hearing loss, as needed (See Attachment B: "Standards for Early Intervention Service Providers....").

# III. QUALITY INDICATORS FOR EARLY INTERVENTION PROGRAMS

Quality Indicators are quantifiable goals or targets by which an early intervention program can be monitored and evaluated. Indicators are used to evaluate progress and to point to needed next steps in achieving and maintaining a quality early intervention program (O'Donnell & Galinsky, 1998). All infants should be served as described below.

- 1. Infants with hearing loss should be enrolled in a family-centered early intervention program within 45 days of confirmation of hearing loss.
- 2. Families should receive intervention from professional personnel who are knowledgeable about the communication needs of infants with hearing loss.
- 3. Infants with hearing loss and no medical contraindication should begin use of amplification when appropriate and agreed on by family within 1 month of confirmation of hearing loss.

- 4. Infants with amplification should receive ongoing audiologic monitoring at intervals not to exceed 3 months.
- 5. The goal for all infants enrolled in early intervention programs is to achieve language milestones in the family's chosen communication mode similar to that for hearing peers of a comparable developmental age. Language growth should be monitored at periodic intervals (i.e. 6-month intervals) to assess progress.
- 6. Families should participate and express satisfaction with the intervention program.

# IV. MONITORING SYSTEM FOR MICHIGAN

The monitoring system for reporting a child's entry into, and progress in, early intervention is an important part of the Michigan Early Hearing Detection and Intervention System. The *Early On* ® Michigan reporting system, already in place, should assist in notifying the MDCH/EHDI Program (FAX: (517) 335-8036) of a child's enrollment into early intervention services as needed, with consent of the parent(s)/caregiver(s).

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#### MICHIGAN'S EARLY HEARING DETECTION AND INTERVENTION SYSTEM <u>ATTACHMENT A:</u>

Early On ® Michigan Referral Process to Intervention for Infants with Hearing Loss



#### Early Intervention 45

MADHS-COALITION FOR DEAF AND HARD-OF-HEARING PEOPLE, EARLY IDENTIFICATION SUBCOMITTEE 2929 COVINGTON COURT SUITE 200, LANSING MI• 48912-4939 PHONE: 517 487-0066 • FAX: 517 487-2586

# ATTACHMENT B:

## Standards for Early Intervention Service Providers: Infants/Toddlers Who are Deaf/Hard of Hearing and Their Families

Children who are deaf or hard of hearing and families of these children have unique needs specific to the hearing loss. These unique needs reflect the challenges children with hearing loss encounter related to their lack of full access to communication. In order to meet the needs of these children and their families, interventionists require expertise in specific areas. The competencies are organized into seven areas:

- 1. Effects of hearing loss on child development, birth-three years of age.
- 2. Working with families.
- 3. Facilitating communication development.
- 4. Maximizing auditory potential and management of sensory devices.
- 5. Developmental assessment and interpretation.
- 6. Developing and implementing the Individual Family Service Plan (IFSP).

7. Awareness of new developments in intervention for children with hearing loss. This list provides a comprehensive guide for knowledge and skills of staff, but can also be used as an inclusive guide to the breadth of information, which should be shared, over time, with the family of the newly identified child with hearing loss.

- I. Effects of Hearing Loss on Child Development, Birth-Three Years of Age
  - A. <u>The interventionist must know:</u>
    - 1. Birth-three child development, including cognitive, language, emotional, motor and social skills.
    - 2. The importance of the interaction of cognition and language.
    - 3. The effects of hearing loss on development.
    - 4. That cognitive development should progress in a parallel fashion to that of hearing children.
    - 5. The effects of the following variables on the development of the child who is deaf or hard of hearing: age of onset of hearing loss, age of identification of hearing loss, age of amplification, age at which initial communication was established, and age at which educational intervention was initiated.
  - B. <u>And be able to:</u>
    - 1. Assist parent(s)/caregiver(s) with strategies to develop communication with their child who is deaf or hard of hearing during daily activities.
    - 2. Share information with families on fostering their child's emotional growth and social development.
    - 3. Assist families in developing ways to foster cognitive development of birth-three year old children who are deaf or hard of hearing.
    - 4. Encourage families to expect their child to meet developmental milestones when possible.

- II. Working with Families
  - A. <u>The interventionist must know:</u>
    - 1. The diversity of the family's structures, roles, values and beliefs, and coping skills.
    - 2. The racial, ethnic, cultural and socioeconomic diversity of the family.
    - 3. The effect of hearing loss and special needs on the relationships within the family and community.
    - 4. Deaf culture and issues of cultural diversity as they may affect children who are deaf or hard of hearing and their families.
    - 5. The significance of the family centered approach to intervention and services in natural environments.
    - 6. The range of educational and other related services (e.g. occupational therapy, physical therapy, etc.) available for the child and family.
    - 7. Resources available for deaf and hard of hearing children and their families including local, state, and national organizations, books, videos, and other reading materials.
    - 8. Federal, state, and local funding sources for infants and toddlers who are deaf or hard of hearing.
  - B. <u>And be able to:</u>
    - 1. Coordinate/participate in family-directed assessment of the family's resources, priorities, and concerns related to the developmental needs of the child within the family context.
    - 2. Provide information to families about historical and current educational and sociological issues related to individuals who are deaf or hard of hearing.
    - 3. Respect family values and decisions regarding their child's and families' priorities, needs, and services.
    - 4. Provide information to families regarding financial, educational and emotional support, in a sensitive non-biased manner.
    - 5. Establish family-professional collaboration and partnership.
    - 6. Facilitate parent(s)/caregiver(s)-professional collaboration.
    - 7. Provide services in the child's natural environment.
    - 8. Adapt to the needs of the individual child and family.
    - 9. Involve parent(s)/caregiver(s) of children with hearing loss with other families of infants/toddlers with hearing loss as a source of information and emotional support.
    - 10. Involve adults who are deaf or hard of hearing and families of children who are deaf or hard of hearing as resources for children with hearing loss and their families.

- III. Facilitating Communication Development
  - A. <u>The interventionist must know:</u>
    - 1. Stages of language acquisition.
    - 2. Potential effects of hearing loss on language acquisition.
    - 3. First language acquisition and effects of hearing loss.
    - 4. Various language/communication approaches used by children who are deaf or hard of hearing (American Sign Language, Auditory-Oral, Auditory-Verbal, Cued Speech, Manually Coded English Total Communication).
    - 5. Communication development including visual/gestural/manual and auditory/oral.
    - 6. Techniques for facilitating spoken and sign language acquisition for children, birth-three, who are deaf or hard of hearing.
    - 7. Assess the ongoing communication development of the child and provide feedback to parent(s)/caregiver(s).
  - B. <u>And be able to:</u>
    - 1. Help the family in determining the child's strengths with respect to communication.
    - 2. Facilitate family understanding of language and communication options and assist the family in selecting an appropriate approach for the child.
    - 3. Evaluate the child's language skills and implement a language/communication approach that is appropriate for the child and supported by the family.
    - 4. Share evaluation of child's language with parent(s)/caregiver(s) and involve them in the step-by-step process of language development.
    - 5. Communicate proficiently in the child and family's selected mode of communication and primary language.
    - 6. Teach the child the skills needed to successfully communicate in the selected mode.
    - 7. Facilitate parent(s)/caregiver(s) and child interactions.
    - 8. Facilitate access to adult and peer communication in the child's primary language and communication mode.
    - 9. Provide information to families about the differences in quality and quantity of incidental language/learning experiences that individuals who are deaf or hard of hearing may experience.
    - 10. Assess and provide feedback to the parent(s)/caregiver(s) regarding their communication interactions with the child.

- IV. Maximizing Auditory Potential
  - A. <u>The interventionist must know:</u>
    - 1. Pre- and postnatal development of the auditory system and audition.
    - 2. The sequence of auditory development (detection, discrimination, identification, and comprehension) and how to integrate those processes into training.
    - 3. Potential effects of sensory devices (e.g. hearing aids, tactile aids, cochlear implants) on the use of residual hearing.
    - 4. That the parent(s)/caregiver(s) may prefer not to use amplification with their child.
    - 5. Characteristics and appropriate applications of various types of sensory devices.
    - 6. Troubleshooting techniques for sensory devices.
    - 7. Effects of room acoustics (noise, reverberation, and distance) on speech recognition and environmental modifications to enhance listening environment.
    - 8. Behavioral and electrophysiological techniques for assessing infants and toddlers.
  - B. <u>And be able to:</u>
    - 1. Generalize the audiological evaluation results.
    - 2. Respect the families' values and choices regarding the use of residual hearing/amplification.
    - 3. Determine and describe the child's level of auditory skills.
    - 4. Implement a program of auditory skill development.
    - 5. Support and train families in appropriate use, care, and maintenance of sensory devices.
    - 6. Observe, evaluate and provide feedback to parent(s)/caregiver(s) on the ongoing effectiveness of sensory devices.
    - 7. Establish a partnership with the managing audiologist to encourage collaboration on assessment, performance, and needs.
    - 8. Integrate auditory and visual information for speech perception as appropriate.
- V. Developmental Assessment and Interpretation
  - A. <u>The interventionist must know:</u>
    - 1. Hearing and other related conditions and their effect on early development of cognition, communication, speech, motor, adaptive and social-emotional development.
    - 2. Medical conditions, genetics, risk factors, syndromes and common etiologies associated with hearing loss.
    - 3. Assessment tools appropriate for birth to three year old children with hearing loss.
    - 4. The dynamic, ongoing process of assessment and management which requires a variety of skills and techniques.

# B. <u>And be able to:</u>

- 1. Determine the potential effects of hearing loss for individual children.
- 2. Separate the effects of hearing loss from those language differences not related to hearing if there are indications present.
- 3. Separate the effects of language problems related to hearing loss from those related to cognitive problems if there are indications present.
- 4. Incorporate information about hearing loss and language of choice to modify assessment procedures. Child assessment should be done using the child's language/communication mode when he/she has enough language to participate.
- 5. Assess current levels of development and needs including those of the family.
- 6. Communicate results of assessment(s) with family input and participation.
- 7. Coordinate/participate in comprehensive assessment of the child including relevant professionals and family participation.
- 8. Summarize and integrate assessment information into an educational report and program plan.
- VI. Developing and Implementing the Individual Family Service Plan (IFSP)
  - A. <u>The interventionist must know:</u>
    - 1. Legislation related to the provision of services to families with children birth to three.
    - 2. Legal rights and due process procedures available for families and children.
    - 3. Child advocacy agencies and other community service agencies.
    - 4. Range of services appropriate to meet the individual needs of the child and family.
  - B. <u>And be able to:</u>
    - 1. Provide families with information pertaining to federal, state, and local legislation for children who are deaf or hard of hearing.
    - 2. Communicate family rights regarding services and confidentiality issues.
    - 3. Recognize expertise and roles of members of the multidisciplinary team.
    - 4. Involve families as equal partners on the multidisciplinary team.
    - 5. Coordinate/participate in IFSP meetings in which family is encouraged to be an active participant.
    - 6. Recognize family strengths and challenges and incorporate these in the IFSP.
    - 7. Coordinate/participate in development of expected outcomes for child and family, with family participation.
    - 8. Facilitate sharing, consulting, joint goal setting and planning with all members of the team.
    - 9. Develop and implement an appropriate implementation plan to address targeted areas.

- VII. Awareness of New Developments in Intervention for Children with Hearing Loss
  - A. <u>The interventionist must know:</u>
    - 1. Current research findings.
    - 2. Technological advancements.
    - 3. Curriculums and instructional materials available.
    - 4. Innovative instructional strategies.
    - 5. Current issues in the field, philosophical views.
  - B. <u>And be able to:</u>
    - 1. Share current literature in the field.
    - 2. Be involved in organizations related to education of children who are deaf or hard of hearing.
    - 3. Network with other professionals.
    - 4. Attend conferences, conventions, and workshops.

\*Adapted from guidelines created by Colorado's Early Intervention Task Force.

# ATTACHMENT C:

Eligibility for Early On and Special Education Services

Criteria for Hearing Impaired for Early On® Michigan

From the State Plan for Michigan under Part C, the Infant and Toddler Early Intervention Services System, *Early On*® Michigan.

http://www.mde.state.mi.us/off/sped/EARLY-ON/LAW%26POLICY/StatePlan.pdf

Page 20. State Eligibility Criteria and Procedure

Established Conditions

- (a) Children with established conditions are those from birth through age two who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.
- (b) The categories of established conditions are (but not limited to):(5) Sensory disorder
- (c) Established conditions will be determined by informed clinical opinions, judgments, and diagnoses which result from the review of multiple sources of information shall include at a minimum;
  - (1) A developmental history as currently reported by the parent(s) and/or the primary caregiver
  - (2) An observational assessment of the infant or toddler with parent(s) and/or the primary caregiver
  - (3) A recent health status appraisal; and
  - (4) An appropriate formal assessment measure (standardized developmental test, inventory, or a behavioral checklist). This formal measure shall not be used as the sole criterion to determine the absence of delay.

## Hearing impairment determination for Special Education

From the Revised Administrative Rules for Special Education (Includes revisions effective June 6, 2002, and selected federal regulations), Michigan Department of Education, Office of Special Education and Early Intervention Services, November 2002. Part 1. General Provisions, Page 4.

R340.1707 Hearing impairment explained; determination. Rule (7).

(1) The term "hearing impairment" is a generic term which includes both students who are deaf and those who are hard of hearing and refers to students with any type or degree of hearing loss that interferes with development or adversely affects educational performance. "Deafness" means a hearing impairment that is so severe that the student is impaired in processing linguistic information through hearing, with or without amplification. The term "hard of hearing" refers to students with hearing impairment who have permanent or fluctuating hearing loss which is less sever than the hearing loss of students who are deaf and which generally permits the use of the auditory channel as the primary means of developing speech and language skills.

(2) A determination of impairment shall be based upon a comprehensive evaluation by a multidisciplinary evaluation team, which shall include an audiologist and an otolaryngologist or otologist.