The EHDI Provider Puzzle: Putting It Together in the Comfort of Your “Medical Home”

There is an “I” in Team

Daniel Montero, M.D., FAAFP
National EHDI Conference
March 8, 2009
Financial Disclosure Information

- I have no relevant financial relationship with the manufacturers of any commercial products and/or provider of commercial services discussed in this CME activity.

- I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.
The National Center for Medical Home Implementation supports medical home implementation in order to ensure that all children and youth, including those with special health care needs, have the services and support necessary for full community inclusion.

www.medicalhomeinfo.org
www.medicalhomeinfo.org

- GO TO Screening Initiatives
- Newborn and Infant Hearing Screening Activities
- EHDI Related Articles
- Fact Sheets
- Early Hearing Detection & Intervention (EHDI) Programs
- **Resources and Tools**
  - Hearing Screening Coding Fact Sheet for Primary Care Providers
  - Denial Management and Contract Negotiation for Hearing Screening Services
- Pediatric Resource Guide to Infant and Childhood Hearing Loss
- Universal Newborn Hearing Screening, Diagnosis, and Intervention-Guidelines for Pediatric Medical Home Providers
- Universal Newborn Hearing Screening, Diagnosis, and Intervention Patient Checklist for Pediatric Medical Home Providers
Universal Newborn Hearing Screening, Diagnosis, and Intervention Guidelines for Pediatric Medical Home Providers

Ongoing Care of All Infants* From the Medical Home Provider

- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Provide vision screening and referral as needed
- Provide ongoing developmental surveillance and referral to appropriate resources
- Identify and refer for audiologic monitoring infants who have the following risk indicators for late-onset hearing loss:
  - Parental or caregiver concern regarding hearing, speech, language, and/or developmental delay
  - Family history of permanent childhood hearing loss
  - Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or auscultation tube dysfunction
  - Perinatal infections associated with sensorineural hearing loss including bacterial meningitis
  - In utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis
  - Neonatal indicators—specifically hypotension and lethargy 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
  - Syndromes associated with progressive hearing loss such as neurofibromatosis, otosclerosis, and Usher syndrome
  - Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth disease
  - Head trauma
  - Recurrent or persistent otitis media with effusion for at least 3 months

*OAE = Otoacoustic Emissions, ABR = Automated Auditory Brainstem Response, IDEA = Individuals with Disabilities Education Act

Before

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss, or loss to follow-up, also may be referred directly to Pediatric Audiologic Evaluation.

(b) Part C of IDEA* may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Infants who fail the screening in one or both ears should be referred for further screening or Pediatric Audiologic Evaluation.

(d) Includes infants whose parents refused initial or follow-up hearing screening.
### Patient Checklist for Pediatric Medical Home Providers

#### Hospital-based Inpatient Screening Results (OAE/AABR)

- **Left ear:**
  - Missed
  - Incomplete
  - Refer\(^a\) \(^c\)
  - Pass
- **Right ear:**
  - Missed
  - Incomplete
  - Refer\(^a\) \(^c\)
  - Pass

**DATE:** _____/_____/_____

#### Outpatient Screening Results (OAE/AABR)

**DATE:** _____/_____/_____

- **Left ear:**
  - Incomplete
  - Refer\(^a\) \(^c\)
  - Pass
- **Right ear:**
  - Incomplete
  - Refer\(^a\) \(^c\)
  - Pass

#### Pediatric Audiologic Evaluation\(^b\)

**DATE:** _____/_____/_____

- **Hearing Loss**
- **Normal Hearing**

#### Documented child and family auditory history

**DATE:** _____/_____/_____

- Report to State EHDI Program results of diagnostic evaluation
- Refer to Early Intervention (IDEA, Part C)
- Medical & Otologic Evaluations to recommend treatment and provide clearance for hearing aid fitting
- Pediatric Audiologic hearing aid fitting and monitoring
- Advise family about assistive listening devices (hearing aids, cochlear implants, etc.) and communication options

#### Enrollment in Early Intervention (IDEA, Part C)

**DATE:** _____/_____/_____

- Transition to Part B at 3 years of age
- Medical Evaluations to determine etiology and identify related conditions
  - Ophthalmologic (annually)
  - Genetic
  - Developmental pediatrics, neurology, cardiology, and nephrology (as needed)

#### Ongoing Pediatric Audiologic Services

**DATE:** _____/_____/_____

---

\(^a\) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss, or loss to follow-up, also may be referred directly to Pediatric Audiologic Evaluation.

\(^b\) Early Intervention (IDEA, Part C) may provide diagnostic audiologic evaluation services as part of Child Find activities.

\(^c\) Infants who fail the screening in one or both ears should be referred for further screening or Pediatric Audiologic Evaluation.

\(^d\) Includes infants whose parents refused initial or follow-up hearing screening.

---

**Patient Name:**

**Date of Birth:** _____/_____/_____

**Ongoing Care of All Infants\(^d\):**

- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Vision screening and referral as needed
- Ongoing developmental surveillance/referral
- Referrals to otolaryngology and genetics, as needed
- Risk indicators for late onset hearing loss:

**Service Provider Contact Information**

- **Pediatric Audiologist:**
- **Early Intervention Provider:**
- **Other:**
- **Other:**
- **Other:**

---

This project is funded by an educational grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services.
Primary Care Provider’s Role

Medical Home

“Pediatricians, family physicians, and other allied health care professionals, working in partnership with parents and other professionals such as audiologist, therapists, and educators, constitute the infant’s medical home.”

JCIH 2007
What do families want to know when a child is diagnosed with hearing loss....

- **What** do we do next?
- **When** must we take action?
- **Where** do we get more information?
- **How** do we decide?
- **Who** will help us?
- **Why** do we need early intervention?
Emotions of Families with a Deaf or Hard of Hearing Baby

(Grief) Reactions to Unexpected Diagnosis
(Pressure) Urgency of Communication Decisions Search
(Confusion) Search for Experienced Professionals
(Isolation) Availability of Services and Support
Medical Intervention

Primary Goals

1. Identify the etiology of the hearing loss to help the family anticipate their child’s needs as well as those of the siblings

2. Prevent or diminish the impact of secondary medical concerns (ie vision, middle ear disease, immunizations)

3. Appropriate referrals and ongoing care
Just in Time

So Your Patients Care Is Right On Time

1-3-6 Plan

1 Before ONE month of age:
   Hearing Screening

3 Before THREE months of age:
   Hearing Diagnostic Audiological Evaluation

6 Before SIX months of age:
   Early Intervention
No Later Than 1 Month

- Ensure hearing screening for all newborns
- Review results & risk factors for late onset or progressive hearing loss with parent/guardian
- Schedule diagnostic audiological evaluation for all “Refers”
No Later Than 3 Months

• Schedule a pediatric diagnostic audiological evaluation for babies who do not pass the initial screen or re-screen.

• If a diagnosis is confirmed:
  – Refer to Early Intervention (Part C)
  – Schedule ENT, Ophthalmology exam, Genetics
  – Provide medical clearance for hearing aids/cochlear implants/therapies if chosen by the family
  – Provide medical referrals: Neurology, Developmental Pediatrics, Cardiology and Nephrology
No Later Than 6 Months

- Complete the ENT evaluation
- Provide pediatric audiologic services including ear molds, hearing aids, information about cochlear implants, follow up etc.
- Enroll child in Early Intervention Services (Part C)
- Provide family with information regarding communication options
- Communicate with family and other service providers for continuity of care
Knowledge is Power

Need for referral to geneticist?
- 11% Pediatricians
- 3% Family Physicians
- 22% ENTs

Need for referral to ophthalmologist?
- 1% Pediatricians
- 0% Family Physicians
- 7% ENTs
“Nearly 40% of children identified with hearing loss and their families are not referred to the Part C early intervention system and may not be aware of the broad array of services and funding available to them. Part C is the primary source for families to link to other medical, audiologic and intervention services.”
Part C of IDEA

- Early Intervention Program for Infants and Toddlers with Disabilities. Est. 1986
- Federal grant program assists states in operating a comprehensive statewide program of EI services for infants and toddlers, ages birth through age 2.
- Statewide early intervention systems differ in many ways from state to state.
Evaluation and Assessment

- Under IDEA, evaluation and assessments are to be provided at no cost to the parent.
- *Evaluation* refers to the process used by the multidisciplinary team (qualified people in the areas of speech and language skills, physical abilities, hearing and vision, and other important areas of development) to find out whether or not your child is eligible for early intervention services.
Eligibility for Part C

- Part C eligibility is determined by each state's definition of developmental delay.
- Includes clinical opinion of professionals with experience in the development of young children.
- States have been given a lot of discretion for determining eligibility for entry into programs.
- Only half of states include EI services to children with mild or unilateral hearing losses.
- If your child is determined to be eligible, the next step is to create an IFSP.
Individualized Family Service Plan (IFSP)

• IFSP documents and guides the early intervention process for children with disabilities and their families. It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate the child's development.

• Family members and service providers work as a team to plan, implement, and evaluate services specific to the family's concerns, priorities, and available resources*.

• A service coordinator then helps the family by coordinating the services outlined in the IFSP.
Example

- Listening and Spoken Language (includes Auditory-Verbal or Auditory-Oral)
- Hearing aids and earmolds needed
- Speech therapy and Occupational therapy
- Requested AV Therapist
- $5,000 per year allowance in services
From Part C to Part B

• IFSP team should start preparing for transition into Part B (Special Education) around 30 months of age

• An exit IEP (Individualized Education Plan) is made to determine the services that your child will receive after transition

• IDEA includes Child Find mandate which requires all schools to identify, locate and evaluate all children with disabilities
Resources

- Part C service coordinator/IFSP
- Other families*
- Physicians, speech therapists, OTs etc…
- National organizations focused on communication method chosen
- AAP state Chapter Champion
- Local schools/special education dept.
Resources

• Early Intervention

• Parent-to-Parent

• Physician support

• Contact State EHDI Coordinator – see www.infanthearing.org
  • www.nectac.org
  • www.handsandvoices.org
  • www.beginningssvsc.com
  • www.babyhearing.org
  • www.aap.org
  • www.medicalhomeinfo.org
Physician Resources

http://www.medicalhomeinfo.org/screening/hearing.html

ALSO: hearing loss module on
http://www.pedialink.org

http://www.cdc.gov/ncbddd/ehdi/
Questions?

Thank you!

Contact Information:
Daniel Montero, MD, FAAFP
dpm06@yahoo.com